

MASS.  
HS40.10:  
1-5/1

\* UMASS/AMHERST \*



312066 0281 5715 5



MASS. HS40.10: 1/1 - 5/1  
Bend as is ✓

HUMAN RIGHTS NEWSLETTER  
Office for Human Rights  
Massachusetts Department of Mental Health

Vol. 1, No. 1

September 27, 1985

FIRST ISSUE OF HUMAN RIGHTS NEWSLETTER

This is the first issue of a Newsletter that will be published every few months for Human Rights Committees (HRCs) and Human Rights Officers (HROs) of the Massachusetts Department of Mental Health. If you know of HRCs or HROs who are not receiving the Newsletter, or have suggestions concerning what should be included in future issues, please contact Vartan Artinian, Office for Human Rights, Dept. of Mental Health, 160 N. Washington Street, Boston, Mass. 02114; (617) 727-1969.

HR NETWORK

Many participants in the conference on "Human Rights of Individuals with Mental Disabilities" held June 8 at the University of Massachusetts/Amherst expressed a need for a statewide Human Rights Network. Human Rights Committee (HRC) members and Human Rights Officers (HROs) advocated the establishment of a "grass roots" network through which they could exchange information and work together to better understand and perform their roles. This Newsletter is intended to foster the growth of such a network through: (1) providing a forum for exchanging information on methods of approaching human rights issues; (2) publishing notices of meetings, training sessions, conferences; (3) providing information from the Office for Human Rights (OHR) to all HRCs and HROs on recent developments in law, regulations, and policies; studies of human rights issues; and other relevant matters.

In order for the Newsletter to serve these functions effectively (especially function (1)), HROs and HRC members must contribute information -- news of your activities; descriptions of how you have handled particular problems; questions regarding difficult issues; etc. Please

send items that you want to share with the Network, letters to the Newsletter's editor, and any other ideas on how to make this publication more useful, to: Vartan Artinian, Office for Human rights, Dept. of Mental Health, 160 N. Washington Street, Boston, Mass. 02114.

INVESTIGATIONS

The HRC: Role and Responsibilities

As part of its role as a monitor of clients' rights, an HRC may sometimes participate in the process for the investigation of a complaint. It can take part in an official investigation in either of two ways: First, an HRC has a duty to monitor closely any investigation involving an "incapable" client, one who has been found not to be capable of initiating or participating effectively in the complaint process. (See 104 C.M.R. §24.02.) The person in charge is required to give notice to the HRC whenever any client is incapable, and the HRO must keep a list of such clients (104 C.M.R. §§24.11(2)(a) and (b)). When the person in charge receives any complaint involving an incapable client, he or she must immediately provide a copy to the HRC (104 C.M.R. §24.11(d)). The HRC is required to help an incapable client file



a complaint (if necessary) and obtain, where appropriate, an independent advocate from a list which the HRC must maintain (104 C.M.R. §24.11(2)(e)). However, this role does not make the HRC a "party" to the action.

If the HRC has reason to believe that the program's investigation is not being conducted properly, i.e. according to DMH Regulations 104 C.M.R. §24.00, it may become a "party", to the complaint by giving written notice to the official before whom the matter is pending. [Note: The HRC would also be a party if it had filed the original complaint on behalf of a client.] As a party, the HRC will be entitled to receive copies "of all reports, plans, notices and other significant documents" relevant to the case. (104 C.M.R. §24.11(3)). It will also have the right to appeal (Id.). Thus, as a party, the HRC has a much greater role and much more impact on the program's investigations process.

An HRC may conduct its own, informal, independent investigation regardless of whether it is a party in the program's investigation or the client is incapable. To determine whether an independent investigation is necessary, the HRC should first interview the Director and discuss the problem with the HRO to attempt to understand and resolve it. If necessary, the HRC or its designated subcommittee may then interview clients, staff, and others and review all relevant records.

In order to facilitate its own investigation process (as well as to monitor activities), the HRC, early in its existence, should work with the Program Director to develop a "protocol" (a memorandum of understanding) setting forth the Committee members' rights of access to records, staff, and clients when authorized by the HRC for investigative or monitoring purposes. The protocol should be signed by both the Program Director and HRC Chairperson; copies should be provided to HRC members

and program staff. Then, when particular HRC members are assigned specific monitoring or investigative responsibilities requiring access to records or individuals, the Committee Chairperson should provide them with written, signed statements authorizing the required access.

If the HRC should determine that the program's official investigation is insufficient, it may either file a complaint of its own or, as noted previously, if it believes the regulations are not being complied with, it may become a party by giving written notice. Such action may, for example, be appropriate in situations where an investigations report is overdue and the investigator has failed to respond to requests for the report.

Although the HRC has no power to take action against staff members or to enforce appropriate policies, it can forward a copy of the findings of its own informal investigation to the Program Director, HRO, and client involved. If unable to resolve a problem at the program level, it may then refer its findings and recommendations to the DMH area, District, or Central Office, in that order, for further action. In the case of state schools or hospitals, Department protocol would dictate going to the District Office first, then the Central Office. In instances where the Committee feels that an issue may constitute a licensing problem or a violation of federal regulations, it may wish to refer the problem directly to the District Licensing Coordinator or the DMH Central Office. In some cases, referring the client to a private attorney or advocate may be appropriate (104 C.M.R. §24.11(2)(e)). The HRC should maintain a list of attorneys and advocates for this purpose.

The HRC may also conduct a follow-up review within a reasonable time to determine whether proper corrective actions have been taken. It should also

work with the program to find appropriate solutions whenever such help would be useful. Although the HRC has no formal enforcement powers, it can still serve as a very effective force for change.

## STATISTICS

### Use of Restraints in DMH Mental Health Facilities

The Office of Human Rights (OHR) has issued a "Preliminary Study of Seclusion and Restraints" (May 29 and June 7, 1985). The study illustrates patterns in the use of these practices in Massachusetts state hospitals, mental health centers, and child/adolescent units. Based upon the Department's "Monthly Facility Report," it compares rates of use among these three types of facilities, among facilities of each type, and among units in each state hospital.

The study reports the number of hours that clients were restrained or secluded per day. It finds that state hospitals had the lowest rate of use. They restrained or secluded clients for an average of 1.5 hours/day which amounted to 14.6% of the total numbers of hours recorded by all state mental health facilities. They also restrained or secluded the fewest (14.3%) of their clients. Among state hospitals, the rate of use varied widely, from a high of 2.9 hours/day at one facility, to a low of 0.7 hours/day at another.

Mental health centers restrained or secluded 24.2% of their clients. The average number of hours/day was 2.6, which represented 25.3% of the total hours of use of restraints and seclusion among all types of mental health facilities. Among mental health centers, the rate of restraint and seclusion varied widely from a high average of 5.7 hours/day at one center, to reportedly no use whatsoever at another center.

Child/adolescent units reported the highest rate of use. They restrained or

secluded 75.9% of their clients for an average of 6.2 hours/day, which represented 60% of the total hours of use by all facilities. The rate of use between these facilities varied enormously. One facility restrained or secluded 93.6% of its clients for an average of 12.06 hours/month. The other facility restrained or secluded only 2.8% of its clients for only 0.27 hours/month.

Among the factors which the report speculates may help account for the large variations in use are: variations in reporting (due in part to differing understandings among professionals of what techniques and devices should be characterized as seclusion or restraint); differences in staffing ratios and levels of training; differences in facilities' square footage; the types of client populations served; different treatment philosophies; and variations in levels of overcensus.

OHR requests that comments on the report be sent to Larry Wheeler, Office for Human Rights, Dept. of Mental Health, 160 N. Washington Street, Boston, MA 02114. Copies of the report are available from Larry.

## PROPOSED REGULATIONS

In the past six months, the Massachusetts Department of Mental Health (DMH) has issued proposed regulations in four areas of interest to HRCs and HROs: seclusion and restraint, youth treatment programs, behavior modification, and research involving human subjects. Copies of all of these are available from the DMH Legal Office, 160 N. Washington St., Boston, MA 02114.

The proposed seclusion and restraint regulations were issued to implement Chapter 464 of the Mass. Acts of 1984. The regulations follow the statute closely, limiting the use of seclusion and restraint to emergency situations and requiring that strict safety measures be taken to ensure a restrained or secluded



client's well being. They require, for example, that a specially trained person remain in attendance with a restrained client and that very frequent checks be made of a client in seclusion. The regulations also set strict limits on the length of time these methods may be employed, who may authorize their use, and how that authorization may be renewed. These proposed regulations were issued for use on an "emergency" basis and will be in effect until September 30 when final regulations are to be issued.

The proposed regulations for youth treatment programs were issued pursuant to Executive Order 244 which requires that teenagers be taken out of adult wards and placed in separate programs to receive treatment appropriate to their age. The regulations create two types of programs. For the treatment of young people in acute crisis, they provide for "Short Term Treatment Programs." Young people in acute crisis would be placed in these programs for up to 90 days, at which time their placement would be reviewed by the program's utilization review committee. Adolescents in need of long term care "in a secure setting" would receive treatment in "Intensive Residential Treatment Programs" (IRTPs). No youth would be admitted to either setting without first being found committable under M.G.L. c.123 §12. All teenagers would be eligible for these programs up until age 19; those receiving special education services would be eligible until age 22. Both programs are to be conducted in as "homelike" a setting as possible, although the proposed IRTP regulations would permit them to be located on hospital grounds. Final regulations are expected before the end of the year.

The proposed research regulations were issued pursuant to 45 C.F.R. §46.00. They give research committees somewhat greater control than in the past over their own membership and also clarify the division of authority between the Central and Facility Research Review Committees.

As HRCs also bear responsibility for ensuring that their clients' rights are not violated in research projects, they should maintain contact with their Facility Research Review Committee to keep informed of research projects involving their program being planned or conducted and their potential risks to clients.

The Department has also published preliminary regulations on behavior modification. Issued for informal comment only, the regulations deal primarily with the use of aversion and deprivation techniques. They divide these techniques into three different categories according to the level of intrusiveness, restrictiveness, and degree of risk. Level I includes those programs which "involve more than a minimal degree of risk, intrusion, restriction on movement, or possibility of physical or psychological harm." The proposal would permit inclusion in an ISP of such "Level I" techniques as overcorrection and withholding non-nutritious food items with the approval of the client or guardian and a designated psychologist or psychiatrist. Level II programs would be those involving a greater than minimal, but not significant, risk, intrusion, restriction, etc. "enforced over the client's resistance." These procedures, including use of bad tastes and odors and firm, but gentle, holding, would require the additional approval of the program's HRC. Level III programs would contain a greater degree of risk, intrusion, or possibility of harm, and would require both HRC and probate court approval.

The proposed regulations would permit the use of restraints to be written into behavior plans. They would also permit the use of "confinement time out." Because of strong initial reactions to these proposed regulations, it is probable that substantial changes will occur before the final version is issued.

This large volume of new regulations should result in a great deal of work for Human Rights Committees. Not only will HRC members need to become familiar with the regulations, but they must ensure that facility staff members and clients understand them as well. These regulations, especially those governing behavior modification and seclusion and restraint, may require significant changes in the practices currently used in many DMH facilities. HRCs may need to monitor programs even more closely and perhaps conduct staff and client training sessions on the new rights granted and responsibilities imposed by these regulations.

#### PROPOSED LAW

Would empower a few Western Mass. HRCs

to appoint "independent monitors" to make antipsychotic medication decisions for certain mental health patients.

Massachusetts House Bill 6005 would empower Human Rights Committees at Northampton State Hospital and "no more than two community mental health programs" in District I (Western Mass.) to appoint and supervise an "independent monitor" as part of an "administrative review pilot project." The monitor, who may not be a DMH employee, would conduct an informal review of the treatment of certain patients for whom antipsychotic medications are prescribed. Only patients who have not refused the medication and whom physicians have initially determined to be incapable of giving informed consent to such treatment would be affected by the statute. Antipsychotic medication could be administered to these patients for only 24 hours (for clients in institutions) or 72 hours (for those in community programs) unless an independent review has been initiated prior to the end of that period. This informal review would be conducted by the monitor. The monitor would determine: (1) whether the patient is competent to consent to treatment; (2) whether the treating facility had complied with the requirements for prescribing antipsychotic medication; (3)

whether the patient had been informed of his/her right to accept or refuse the medication; and (4) if the patient is incompetent, whether the patient would accept the medication if competent. In making this substituted judgment, the monitor would be required to consult with the client, family members, and the treating clinicians. The patient "may be represented by an attorney, family member, best friend, advocate, or other designated representative during any informal or formal review." For all formal reviews, DMH is required to appoint an independent patient advocate if the patient does not already have one of his/her own choosing. A copy of the independent monitor's decision would be provided to the patient and to the HRO for review by the HRC.

If the monitor finds that there is "a substantial question concerning the patient's consent to treatment with antipsychotic medication," an independent hearing officer appointed by the state Division of Administrative Law Appeals would be required to formally hear the case within ten days after the initiation of treatment. If any authorized party objects to the decision, he or she may appeal to the courts for review. The legislature is expected to take up consideration of the bill during this year's session.

#### OHR:

What is it?

Who is it?

The Office for Human Rights (OHR) was established in February, 1985 to assure the protection of the rights of all clients of the Department. Its major task has been the establishment of a statewide system of human rights committees (HRCs) and human rights officers (HROs), and the institution of efficient complaint mechanisms.

OHR serves as a resource for HROs and HRCs by answering questions on Department



regulations and policies and working with both staff and clients in implementing them. OHR also provides guidance on procedure and methods for investigating complaints. On occasion the office may conduct its own investigation, or closely monitor an investigation conducted by others.

OHR also performs studies on practices which affect clients' rights. It recently issued a "Preliminary Study on the Use of Seclusion and Restraint," summarized elsewhere in this Newsletter. Due out this fall are a "Complaint Log Study" and a "Death Study," analyzing patterns in the frequency and causes of client deaths in DMH facilities. It is hoped that these studies will help reveal those areas in which clients' rights are in most need of protection and reinforcement.

Most of the staff members of OHR became involved in the mental health field because of a deep belief that a respect for human rights must be an integral part of client treatment and care. Larry Wheeler, M.Ed., has worked in a variety of capacities including direct care worker, principal psychologist, and program director at Fernald State School and a community program. As OHR's first director, he sets priorities and policy in conjunction with the office's Advisory Committee, and selects the projects upon which the staff will focus its energies.

Jean Tuller, M.P.A., Clients' Rights Coordinator, who has worked with emotionally disturbed children and with mentally retarded adults at Fernald, serves as the Hearings Administrator for ISP and Investigations Appeals. She also provides technical assistance to human rights officers, acts as a resource for complainants in the investigations process, and works with several Department task forces.

Deb Lashman, M.S.P.E., worked previously in a V.A. hospital and at U. Mass./Amherst's University Health Services. As Clients' Rights Coordinator at OHR, Deb monitors cases, provides technical assistance to HROs in mental health facilities, works on special projects such as the study on seclusion and restraints, and performs a variety of administrative tasks.

Susan Krumholtz is OHR's Legal Liaison. She works with the Department's Legal Office to ensure that concern for human rights is adequately reflected in regulations and policy. She also works on policy issues, provides technical assistance to HROs, monitors cases at Bridgewater State Hospital, and sits on task forces on seclusion and restraint and on violent behavior.

Vartan Artinian, Ph.D., Clients' Rights Specialist, monitors complaints and investigations and has primary responsibility for managing the office. New to the mental health field, Vartan previously taught Middle Eastern studies at Harvard University and at U. Mass./Amherst.

Nancy Rich occupies a half-time position as a Human Rights Trainer. She has long experience in training both professional and lay people in human rights. Nancy also worked as a Program Specialist at Fernald for two years before joining OHR where she coordinates and conducts its human rights training programs.

Mr. Wheeler and his staff invite HRCs and HROs to call upon them for any information and assistance they may need to best protect client rights. That is why they are there.

—



HUMAN RIGHTS NEWSLETTER  
Office for Human Rights  
Massachusetts Department of Mental Health

Vol. 1, No. 2

November 29, 1985

INPUT NEEDED FROM HRCs and HROs

Although response to the first issue of the Newsletter was good, we would like to hear much more from you, the readers. Please tell us which issues are most important to you and how the Newsletter can best address those issues. Tell us how you handle particular problems -- what works, what doesn't work. If you disagree with anything said in the Newsletter, please let us know.

A number of HROs and HRC members have expressed the need for a forum for the exchange of ideas, information, and questions. Here is your forum. The Newsletter is available to present your thoughts on methods of dealing with hard legal and clinical issues; relations with program directors and staffs; notices of meetings; strategies for human rights training of clients, families, and program staffs; dealing with "burn out"; etc. This publication's only purpose is to serve your needs as HRC members and HROs. But to realize its full potential, we need input from you. Please send your ideas, suggestions, and questions to Vartan Artinian, Office for Human Rights, 160 N. Washington Street, Boston, MA 02114; (617) 727-1969.

FINAL REGULATIONS ISSUED

In Issue 1 of this Newsletter, it was reported that the Department of Mental Health had recently issued proposed regulations governing several areas of activity. Final regulations have now been issued in two of these areas: seclusion and restraint and research. These final regulations are available upon request from the Legal Office, Department of Mental Health, 160 N. Washington Street, Boston, MA 02114; (617) 727-8611.

MONITORING THE USE OF  
RESTRAINT AND SECLUSION

What To Look For; What To Do.

One of the most important responsibilities of Human Rights Officers and Human Rights Committees is the review of seclusion and restraint practices.

Historically, seclusion and restraint have sometimes been used as punishment or for staff convenience, rather than for the legitimate purpose of protecting clients and staff when no less restrictive alternative will suffice. Although strict regulations and better staff training now discourage such abuse, careful review of the reasons for, actual method used, and duration of seclusion or restraint in particular instances are still essential.

A major source of information for an HRC and HRO are the authorization forms which must be filled out by staff when seclusion or restraint are implemented. These forms were recently revised to make them compatible with the new law and regulations. DMH has produced an instruction sheet telling staff members how to fill out the forms. If these instructions are followed, the reasons for and method of restraint or seclusion

instructions are followed, the reasons for and method of restraint or seclusion should be apparent to anyone who reads the authorization form. HROs and HRC members should become familiar with these instructions so that they can better assess each restraint or seclusion report.

The first question which the HRC (or HRO) must consider when looking at a seclusion or restraint authorization form is whether the use of these techniques was justified. The committee should examine the portion of the form which calls for a description of the emergency situation and a list of the "behavioral precursors" which led to the decision to restrain or seclude the client. These descriptions should be given in sufficient detail for the reader to form a clear picture of what happened. Vague statements such as "The client was extremely agitated" are not sufficient. Such statements may be attempts to conceal the fact that, although the client's behavior was annoying to staff or other clients, it did not actually constitute a threat of violence to anyone. On the other hand, a statement such as "The client was extremely agitated and began to strike another client with a serving spoon" presents a much clearer picture of a situation in which the use of restraints may be justified.

The authorization form should also describe in detail the less restrictive alternatives which were attempted or considered before restraint or seclusion was ordered, and why these alternatives failed or were not implemented. If physical restraint was employed, the type and manner in which it was used must be specified, as well.

The HRC must determine whether the use of restraint or seclusion was authorized by the correct person. Did the program or facility head, his or her designee, or an authorized physician actually sign the form as the person

authorizing the restraint? If a physician has already signed the form elsewhere, he or she must sign again if he or she is also the person authorizing the restraint or seclusion.

The new regulations require that a staff member or "special" remain in attendance on a restrained client. The HRC should examine the box marked "special" to see whether it has been signed and who signed it. Was the person in attendance one who has been "specially trained to understand, assist, and afford therapy to the person in restraint," as required by the law?

The HRC must make sure that safety checks of the client's "comfort, body alignment, and circulation" were conducted every fifteen minutes. The assignment of a special attendant does not eliminate the need for these safety checks. When a special is not in attendance (an emergency situation that may last not more than two hours), safety checks must be made every five minutes. The HRC should also check to see that the times are proper for each renewal of a restraint or seclusion order.

The regulations require that a separate form be included for patient's comments. If the client refuses to comment on the circumstances of his or her seclusion or restraint, this refusal should be recorded. Thus, there should always be some notation (either comments or indication of a refusal) on the form.

In order to analyze properly the general, overall use of seclusion and restraint in a program or facility, the HRC or HRO should keep track of the patterns and frequency of their use. If certain wards or program components show a disproportionately high number of incidents of seclusion or restraint, the HRC should investigate to try to find out whether this use is warranted. On the other hand, if certain units report an exceptionally low use of restraint



should ascertain that such a plan is actually developed.

HRCs and HROs have important roles to play in the elimination of the inappropriate use of restraint. The Office for Human Rights will provide further information and advice to HRCs and HROs if presented with specific questions concerning the use of restraint or seclusion.

#### BURDEN OF PROOF UNDER THE INVESTIGATIONS REGULATIONS

On July 10, 1985, an appeal of a decision under the DMH Investigations Regulations was decided by an administrative Hearing Officer. This was the first time an appeal under these regulations had progressed to this stage. In deciding the case (In re: Brian B.), the Hearing Officer (Janet L. Shur) clarified an important point regarding the investigation process. She ruled that at the investigatory stage, the burden of proving an accusation "must be placed initially on the complaining party; i.e., the clients on whose behalf the complaint has been brought." The Officer also decided, however, that she was not required in this case to decide who should have the burden of proof at the hearing stage. She referred that question to the DMH General Counsel.

A copy of the decision is available from the DMH Office, 160 W. Washington Street, Boston, MA 02114; or, for \$1.15 (for copying and postage), from Disability Advocates Bulletin, Pike Institute, B.U. School of Law, 765 Commonwealth Avenue, Boston, MA 02215. [Please specify Item #2390 if ordering from Pike Institute.]

#### ATTORNEY PERFORMANCE STANDARDS IN CIVIL COMMITMENT AND GUARDIANSHIP

Human Rights Committees are charged with the duty of providing clients with opportunities to exercise their rights to the fullest extent of their capabilities and interests [104 C.M.R. §§3.10(16)(c), 15.03(13)(c)(3), and 20.14(1)(b)(5)(c)].

Human Rights Officers must assist clients in obtaining legal information, advice and representation through appropriate means, including referral to independent attorneys [104 C.M.R. §§3.10(18)(d), 15.03(13)(g)(4), and 20.14(2)(d)]. Two sets of standards for attorneys, recently published by the Massachusetts Committee for Public Counsel Services (CPCS), should therefore be of interest to HRCs and HROs. One set of standards is for attorneys who wish to receive appointments to represent indigent persons in cases involving civil commitment to a mental health facility; the other is for those seeking appointments to represent persons for whom guardianship with the authority to administer extraordinary medical care has been proposed (a "Rogers-type" guardianship hearing). The standards have been approved by the Mental Health Legal Advisors Committee (MHLAC).

The two standards are quite similar. Both stipulate that "the role of counsel in these cases is to be an advocate for the respondent [client], in opposition to the petition and to insure that the [client] is afforded all of his/her due process and other rights." In both, the attorney must immediately file an appearance in court, inform the client of the assignment, and arrange to meet him/her. If the attorney cannot meet with the client and begin work on the case promptly or, in guardianship proceedings, if the lawyers cannot be in court on the date set, he/she "shall decline the appointment." Throughout the standards, there is an emphasis on keeping the client informed about the proceedings and the client's choices regarding litigation strategy and treatment alternatives. Certain steps are also mandated in the attorney's trial preparation, including detailed examination of records and preparation of witnesses. At the hearing, the attorney is required to "act as a zealous advocate for the client, insuring that proper procedures are followed and that the client's interests are well represented." After either type of hearing, the attorney must meet with the client to explain the court's decision.

The civil commitment standards require that if the court finds that commitment is appropriate, the attorney must explain the

appearance in court, inform the client of the assignment, and arrange to meet him/her. If the attorney cannot meet with the client and begin work on the case promptly or, in guardianship proceedings, if the lawyers cannot be in court on the date set, he/she "shall decline the appointment." Throughout the standards, there is an emphasis on keeping the client informed about the proceedings and the client's choices regarding litigation strategy and treatment alternatives. Certain steps are also mandated in the attorney's trial preparation, including detailed examination of records and preparation of witnesses. At the hearing, the attorney is required to "act as a zealous advocate for the client, insuring that proper procedures are followed and that the client's interests are well represented." After either type of hearing, the attorney must meet with the client to explain the court's decision.

The civil commitment standards require that if the court finds that commitment is appropriate, the attorney must explain the client's rights to appeal and to file a petition for discharge. The attorney must review the evidence to inform the client about "any steps the client can take during the commitment period in order to be discharged from the hospital." In a guardianship hearing, if the guardianship is granted, the attorney must attempt to incorporate into the court's decree a requirement for "periodic review of the client's condition, with provision for changing the decree if the client's condition changes." The attorney should, if necessary, return the case to court for periodic review. The attorney should also consider an appeal.

CPCS is creating a list of attorneys who agree to abide by these standards and

who attend a training session on mental health law. CPCS and MHLAC plan at least four training sessions throughout the state prior to February 1, 1986. The list of attorneys will be distributed to appropriate courts. Only attorneys on this list will be eligible to receive appointments to represent indigent persons in these cases.

Copies of the standards and information about the attorney list and attorney training sessions are available from MHLAC, 11 Beacon Street, Suite 925, Boston, MA 02108 or from CPCS, 80 Boylston Street, Suite 600, Boston, MA 02116.

#### WESTERN MASSACHUSETTS LEGAL SERVICES

A key resource for obtaining independent legal advocacy services in Western Massachusetts is the Center for Public Representation (CPR) in Northampton. Staff of the Center (which originally used the name "Mental Patients Advocacy Project") provide counsel for patients and prospective patients in civil commitment and Rogers-type guardianship hearings; represent clients with special education, SSI, and SSDI claims; serve as counsel for Northampton State Hospital residents and former residents in the Brewster v. Dukakis class action; operate the Disability Law Clinic at Northampton State Hospital and Belchertown State School, in conjunction with the clinical legal program at Western New England Law School; and conduct trainings on human rights issues. For further information, HRCs and HROs are encouraged to contact the Center for Public Representation, Northampton State Hospital, P.O. Box 389, Northampton, MA 01061; (413) 584-1644, X-265.

*Change so this does not imply  
an endorsement, but is one of many  
that will be listed.*





# HUMAN RIGHTS NEWSLETTER

OFFICE FOR HUMAN RIGHTS  
MASSACHUSETTS DEPARTMENT OF  
MENTAL HEALTH

EDWARD M. MURPHY  
Commissioner

Vol. 11, No. 1

April, 1986

## HUMAN RIGHTS AND INFORMED CONSENT

By, Richard Ames

The Department of Mental Health's affirmation of its human rights obligations is the product of many years of vigorous external advocacy and internal administrative decision-making. The history is one of great conflict and debate -- often taking place in the context of dismal failure at Department programs -- in which parents, clients, clinicians, civil rights attorneys, administrators, legislators and many others have participated, often from significantly different perspectives. Controversial interventions such as involuntary hospitalization, restraint and seclusion, transfers of clients between institutions and community residences, and antipsychotic medication are now governed by rules that have been developed in this way. These various requirements all reflect at least in part an effort to protect the human rights of individuals served by the Department.

The legal and policy outcomes of this ongoing debate can at any point in time be stated in deceptively clear, assertive and simple terms. This appearance of finality will never mask for long, however, the extraordinary complexity and the inherently controversial and evolutionary nature of human rights issues when they arise in the context of mental illness and mental retardation. The need for a continuing search for better answers may be illustrated through consideration of the doctrine of informed consent.

The legal right to give or withhold consent to medical treatment interventions is strongly supported at the conceptual level by traditional ethical and clinical consid-

erations. In ethical terms, the assertion of the legal right rests on a recognition of the fundamental value of each person's unique perspective on life. Each individual ought to be free to choose whether or not to permit invasions of his or her body by way of medication or surgery.

The moral force of this assertion is reinforced by the commonplace clinical proposition that a patient's voluntary participation in a course of treatment is likely to facilitate the effectiveness of the treatment.

In 1982, in a case that did not involve mentally disabled individuals, the Massachusetts Supreme Judicial Court articulated the legal requirements for informed consent in the following terms:

(A) physician owes to his patient the duty to disclose in a reasonable manner all significant medical information that the physician possesses or reasonably should possess that is material to an intelligent decision by the patient whether to undergo a proposed procedure. (Harnish v. Children's Hospital, 387 Mass. 152)

In 1983, the Court referenced the Harnish case in its Rogers v. Commissioner decision, confirming that the rule of informed consent applied to medical treatment decisions affecting mentally disabled individuals. As the Rogers decision itself makes clear, however, the transposition of the Harnish rule of informed consent to a human service system that is dedicated to the care and treatment of severely mentally retarded individuals cannot be accomplished without substantial doctrinal innovation.

Policy Memorandum 83-50 was issued by the Department in December, 1983, in response to the Rogers decision. For the medication refusing patient, the policy prohibited the administration of antipsychotic medication absent an emergency or a court order. With respect to medication accepting patients, Policy 83-50 reiterated the Rogers informed consent rule, including the Court's admonition favoring judicial decision-making, but then went on to expressly authorize antipsychotic medication treatment without informed consent and without judicial decision-making in the following circumstances:

(W)hile there must be assurance that all antipsychotic medication programs have been prescribed and are maintained in accordance with accepted medical practices, and that all patients within the limits of their capacity to understand are properly informed as to the risks and benefits of their medication program, the inevitable delays involved in obtaining judicial review where there is passive or active acceptance of the medication will be an insufficient reason by itself to interrupt or not initiate the treatment.

Policy 83-50 sought to resolve an apparent conflict between the Rogers right to informed consent and the equally important right of individuals not to be denied needed treatment solely because of their inability to give informed consent. Today, as in 1983, thousands of individuals who are incapable of giving informed consent are accepting prescribed antipsychotic medication without judicial authorization. They include long-term residents of institutions, individuals who are hospitalized for a few days or weeks, individuals in structured community residential programs, and individuals with regular or irregular outpatient contacts. For some of these individuals, whose treatment is initiated during acute psychotic episodes, stabilization may result from the treatment such that the medication may then be continued or stopped with informed consent. For other individuals, the state of incompetency will persist throughout the course of the treatment.

Enormous progress has been made to date in presenting Rogers cases to the judiciary -- over 1000 cases have been decided to date -- and in gaining significant legislative reforms to facilitate Rogers cases both in the District and in the Probate Courts. The judicial decision-making process, however, appears to be too cumbersome to be relied on as the sole legitimizing agent for a treatment intervention that is used, indeed depended upon, as extensively as are antipsychotics in such a variety of treatment settings and with such disparate patient populations.

The Department is sponsoring in the 1986 legislative session a bill that would allow administrative reviews to substitute for court decisions in the case of individuals whose need for antipsychotic medication and/or incompetency is basically episodic or short-term. Additionally, the Department is sponsoring a bill establishing a public guardianship commission to meet the protective and substitute decision-making needs of individuals who are incompetent and who have been left without family or others to serve as their guardians. Although the guardianship option will not immediately relieve the judiciary of its responsibility to review antipsychotic medication cases, it will greatly facilitate medical treatment decision-making in a wide variety of other situations.

Closing the guardianship gap for individuals who are essentially unrepresented in their personal affairs and providing an alternative administrative review system for relatively short-term antipsychotic treatment decisions are reforms that should be assessed and debated on their respective merits. They should, however, be viewed as part of the larger effort to make the principles of informed consent work within the mental health and mental retardation service system while also ensuring equal access to treatment for all individuals regardless of their capacity to give informed consent.

*Richard Ames is the General Counsel of Massachusetts Department of Mental Health.*



### THIRD ANNUAL HUMAN RIGHTS CONFERENCE

The Office for Human Rights (OHR) of the Department of Mental Health, in conjunction with the Massachusetts Law Reform Institute, is presenting a conference entitled "Controversies in Human Rights."

The conference will be held on Thursday, May 22, 1986 at the Sheraton Inn, Mansfield, Massachusetts, and the program will begin at 9:00 a.m.

The morning will feature a panel discussion on "Aversive Therapy: What place does it have in treatment?" Panelists will include Roderick MacLeish, the attorney representing BRI, and John McGee, a nationally recognized expert on behavioral techniques and an opponent of the use of aversives. The majority of afternoon workshops will probe current controversies, from the aftermath of the "Rogers" decision to the future of the state schools. In addition, there will be practical skills workshops for those wishing to acquire basic skills.

The registration fee, which includes lunch, will be \$21.00. There will be a limited amount of money available to provide subsidies for those who would otherwise not be able to attend.

Detailed brochures will be available in mid-April. Advance registration is strongly encouraged. For additional information contact Vartan Artinian at (617) 727-1969 or Susan Krumholz at (617) 727-5605.

### RIGHTS IN COMMUNITY PROGRAMS By Steven J. Schwartz

For the past two decades, the major developments in the rights of people with mental disabilities have been directed to institutions and the individuals they confine.

With the exception of legal efforts to allow people to leave these institutions through the creation of less restrictive community services, little attention has been paid to ensuring that the choices and rights of persons participating in these community programs are respected.

As a result of the mental retardation and mental health consent decrees, the Department of Mental Health has promulgated detailed regulations governing the rights of clients in any community program funded, licensed, or operated by the agency. Although the two sets of regulations (mental retardation - 104 CMR 20.00, mental health - 104 CMR 15.00) differ in a few respects, they are generally parallel. Both provide important protections with respect to abuse, discrimination, privacy, dignity, and civil rights. Both guarantee clients access to their own records, control over their own property, payment for any work done at the program, freedom from any form of seclusion and most types of restraint, and information concerning the exercise of these rights through a human rights officer.

Two critical provisions of these regulations are often overlooked and unenforced. The first relates to the need to obtain clients' consent (or that of their guardian if they have been found to be incompetent by a probate court) prior to their admission to a program or the administration of medical treatment. For consent to be valid, it must be based upon a full explanation of all relevant information, and it must be free of any threat, duress, or coercion. Thus, clients in community programs cannot be forced into participating in the program -- or any related service such as a day program, work program, therapy, or case management. Nor can they be required to accept medication or other form of treatment as a condition of being in any program.

The second important section of the regulations concerns termination or eviction from a program. The mental health (but not the mental retardation) regulations prohibit terminating a client from any community service, except in an emergency, unless the program has made and documented substantial efforts to address whatever problem the individual is having. Most importantly, the client can not be asked

to leave a community service for exercising a right protected by another provision of the regulations. Therefore, an agency cannot establish a program rule that would require clients to take medication, participate in another community service, or turn over their funds to staff. Nor can it terminate or evict a client for failing to comply with such a rule.

The Department's regulations provide significant guarantees of rights for clients in community programs. The enforcement of these rights will require a substantial effort by consumers, families, advocates, and members of program human rights committees. Given the importance of ensuring that community programs do not become reminiscent of institutions, it is essential that this effort command the primary attention of all persons concerned with the rights of people with mental disabilities.

*Steven J. Schwartz is the Director of Center for Public Representation.*

#### OHR TO HOST NARPA'S SIXTH ANNUAL CONFERENCE

OHR has been selected to host the 1986 conference for the National Association for Rights, Protection, and Advocacy (NARPA). NARPA is an organization with members representing consumer groups, legal advocates, and internal advocacy offices within state mental health agencies, such as OHR. The group has been in existence for several years and is a national force in advancing the rights of individuals with mental disabilities. Notable local NARPA members include Steve Schwartz, Judi Chamberlin, Isaiah Ulls, and Tony Winsor.

The Conference will be held October 15-18, 1986 at the Park Plaza Hotel in downtown Boston. The hotel is offering reduced room rates for out-of-towners. There will be a conference fee of \$70.00 which will include most meals and attendance to all conference events. An aggressive scholarship campaign is underway and we hope to offer at least 50 scholarships to conference attendees.

The structure of the conference will be to cluster most of the workshops into six tracks, with four workshops to a

track. Proposed themes for the tracks include involuntary treatment, advocacy principles, community services, the Protection and Advocacy legislation, strategies for systems change, and reclaiming basic citizenship opportunities. Each track will be organized in a continuum which will begin with an overview of the topic, have two in-depth perspectives on the topic, and finish with a problem-solving session. Additional workshops will explore topics such as criminal justice and recent legal development.

The NARPA conference should provide individuals active in human rights work with a unique and rewarding opportunity to discuss critical issues with other members of the field from across the country. Registration will begin in July with an extensive mail-out. Please contact Jean Tuiler at (617) 727-5605 for further information. We look forward to seeing you at the conference.

#### ARC RESOLUTION ON AVERSIVES

The following is a resolution adopted by the delegate body of the Association of Retarded Citizens (ARC-US), on November 23, 1985 in Reno, Nevada.

WHEREAS, it is in the tradition of this Association to challenge current practices when those practices are inhumane and depersonalizing; and

WHEREAS, research does not support the long term efficacy of aversive behavioral intervention; and

WHEREAS, the use of aversives raises disturbing legal and ethical issues; and

WHEREAS, the use of aversives may diminish the dignity of the administrator and does diminish the dignity of the recipient;

NOW THEREFORE BE IT RESOLVED that ARC/United States calls for a halt to those aversive practices that 1.) deprive food, 2.) inflict pain, 3.) use chemical restraint in lieu of programming; and

BE IT FURTHER RESOLVED that ARC/United States communicate this resolution to the entire membership, advocacy, parent and consumer groups, the media and legislative bodies; and



BE IT FURTHER RESOLVED that ARC/United States promote the use of positive non-aversive techniques and training in these techniques; and

BE IT FURTHER RESOLVED that ARC/United States review those aversive practices listed above and other related practices, revise its policy statement on behavior management in conformance with this resolution, and present the revision to the delegate body at its 1986 annual convention.

#### **YOUR RIGHTS AS AN ELDERLY OR HANDICAPPED VOTER**

Secretary of State Michael J. Connolly, the chief elections officer of Massachusetts, wants to encourage all eligible citizens, including those who are elderly or handicapped, to participate in all Massachusetts elections. To do so, you should know your rights as an elderly or handicapped voter.

#### **YOUR RIGHT TO REGISTER TO VOTE**

To vote, you must first register. Call your City or Town Clerk or Election Commission for times and places of local registration sessions. Registration in Massachusetts is permanent, and you will not have to register again unless you move.

If you cannot go out to register at a registration session, local election officials will come to you. At least six weeks before an election, call or write your City or Town Clerk or Election Commission to request an application, fill it in, and return it so that office receives it at least three days before registration closes for the next election. Two local officials will come to your home, nursing or rest home, or hospital to register you.

#### **YOUR RIGHT OF ACCESS TO YOUR POLLING PLACE**

Most polling places and voting equipment must be accessible to elderly and handicapped voters, for all elections at which a federal office is on the ballot. A few polling places are still not accessible, because officials have decided

that no accessible place can be made available. To learn if your polling place is accessible, call your City or Town Clerk or Election Commission, or call Secretary Connolly's office at the telephone numbers below.

#### **YOUR RIGHT TO VOTE BY ABSENTEE BALLOT**

If your polling place is not accessible, or if you are unable to vote at the polls because of absence from the community, physical disability, or religious belief, you may vote by absentee ballot. Apply in writing to your City or Town Clerk or Election Commission. You have the choice of voting in the Clerk's or Election Commission's office, or of having the ballot mailed to you and returning it by mail. (If you vote at some nursing homes or other health care facilities, local election officials may hand-deliver your absentee ballot to you rather than mail it.) If you are voting by mail, be sure to apply in enough time for the ballot to be mailed both ways before election day.

Some person at least 18 years old must witness you mark your absentee ballot (but not how you vote), and this witness must sign the return envelope. A notary public is no longer needed. If a doctor writes a letter to your City or Town Clerk or Election Commission stating that you are permanently physically disabled, no one need witness your absentee ballot from then on.

#### **YOUR RIGHT TO ASSISTANCE IN VOTING**

Whether you are voting at the polls or by absentee ballot, you can obtain instructions and assistance for voting.

At the polls, an election official will explain how to use the voting equipment. If you are unable to vote because you are physically disabled, or are unable to read or to read English, you may have any person you choose, or two election officials, assist you in marking your ballot or using the voting equipment.

If you are voting by absentee ballot and need this assistance, your witness or any other person can help you vote.

For more information about your right to vote, call or write your City or Town Clerk of Election Commission, or:

Elections Division  
Office of the Secretary of State  
One Ashburton Place -  
Room 1705  
Boston, MA 02108

(617) 727-2828  
(800) 462-VOTE  
(800) 462-8685 (TDD)

#### HOW TO FIND OUT ABOUT YOUR HUMAN RIGHTS

A booklet entitled "How to Find Out About Your Human Rights" is now available at our Office for Human Rights. The booklet has been designed to inform DMH clients of their basic rights and the available resources to help them exercise those rights. A limited number is also available in Spanish. Copies may be obtained by contacting Vartan H. Artinian, Office for Human Rights, Department of Mental Health, 160 North Washington Street, Boston, MA 02114, (617) 727-1969 or (617) 727-2789.

#### SPECIAL THANKS

Special thanks are extended to Mureen Durham, Administrative Assistant here at the Central Office of DMH, for her aid in the preparation of this issue of the Newsletter.

#### EDITOR'S NOTE

The purpose of this Newsletter is to serve the needs of Human Rights Committees and Human Rights Officers of the Massachusetts Department of Mental Health. please send your comments, questions, and issues you wish to be addressed to the Newsletter Editor, Vartan H. Artinian, Office for Human Rights, Department of Mental Health, 160 North Washington Street, Boston, MA 02114; (617) 727-2789.



**•ACCEPTING THE CHALLENGE TO CARE:  
THE RELIGIOUS COMMUNITY AND THE MENTALLY ILL**

**CONFERENCE**

**THURSDAY, MAY 8, 1986**

**9:30 a.m. - 5:00 p.m.**

**Metropolitan State Hospital**

**Waltham, MA**

**Sponsoring Organization**

*Alliance for the Mentally Ill of Massachusetts  
Catholic Charities of the Archdiocese of Boston  
Community Support Program, Dept. of Mental Health  
Episcopal Diocese of Massachusetts  
Genesis 2: An Independent Voice for Jewish Renewal  
Massachusetts Association for Mental Health  
Massachusetts Council of Churches  
St. Nicholas' Chapel at Metropolitan State Hospital  
Social Action Ministries of Greater Boston  
Synagogue Council of Massachusetts*

**A CONFERENCE FOR:**

- Clergy      • Lay Leaders      • Congregants      • Mental Health Providers
- Families      • Consumers      • and others concerned about the future of the  
mentally ill in Massachusetts

**PRESENTORS WILL INCLUDE:**

Rev. Robert Anderson	Rev. Jeffrey Billerbeck	Geoffrey Brahmer
Rev. Emily Chankler	Anne Corapi	Rev. Thomas Curran
Nona Dearth	Dr. Philip DeMattea	Kenn. Dudek
David Engle	Rabbi Ronne Friedman	Blair Geibond
Maureen Goldfarb	Carol Bowers Johnson	Dr. Nancy Kehoe
Rev. Brian Kelley	Dr. Kenneth Larsen	Dr. William Malanud
Rev. Thomas McDonnell	Rev. James Nelson	Rep. Marie J. Parente
Anita Pyatt	Myra Rodrigues	Alex Rodriquez
Rev. Paul Shanley	Carol Smith	Mel Tapper
Sgt. Wayne Urquhart	Rev. Paul Walsh	Rabbi Jerome Weistrop

**REGISTRATION FORM (Please register before April 25th)**

***"Accepting the Challenge to Care:  
The Religious Community and the Mentally Ill"***

Name \_\_\_\_\_

Address \_\_\_\_\_

Church, Synagogue or Other Affiliation \_\_\_\_\_

Registration Fee: \$10. (includes lunch)

*Please make check payable to: St. Nicholas' Chapel. Mail to: St. Nicholas' Chapel, Metropolitan State Hospital,  
475 Trapelo Road, Waltham, MA 02154.*

OFFICE FOR HUMAN RIGHTS  
MASS. DEPT. OF MENTAL HEALTH  
160 NO. WASHINGTON ST.  
BOSTON, MA 02114





OFFICE FOR HUMAN RIGHTS  
MASSACHUSETTS DEPARTMENT OF  
MENTAL HEALTH

EDWARD M. MURPHY  
Commissioner

Vol. 11, No.2

October, 1986

HUMAN RIGHTS COMMITTEE COMPOSITION  
By Larry Wheeler

The Office for Human Rights (OHR) receives many questions regarding the different aspects of Human Rights Committee (HRC) and Human Rights Officer (HRO) functions. As an ongoing feature of this newsletter we will address some of the most frequently asked questions in this column.

The composition of an HRC is governed by Department of Mental Health (DMH) regulations 14 CMR 3.10 (15) for DMH Inpatient facilities, 15.03 (13) (d) for community mental health programs, and 20.14 (1) (c) for mental retardation programs. All HRCs must have a minimum of five members at least three of whom shall be consumers; family of consumers or advocates and not more than one of whom shall have any direct or indirect financial or administrative interest in the program or the Department. For HRCs of mental retardation programs there are two additional requirements: 1) that one member be a physician, allied health professional or psychologist; and 2) that one member be an attorney, paralegal or law student.

It is recommended that for HRCs in mental health programs, consumers should be those people connected with mental health services and for HRCs in mental retardation programs, consumers connected with mental retardation programs. This gives the HRC relevant experience from which to draw.

It is encouraged to have family members or guardians of consumers on an HRC. Many family members have a demonstrated commitment to improving services and advocating. This interest and commitment can be very helpful in sustaining the Committee. However, an HRC should generally not be composed entirely of family members as this may result in a more singular point of view. It is essential to the functioning of the HRC to have representation of many different points of view in order to fully explore the many complex issues facing the Committee.

It is also strongly encouraged to have consumers on an HRC. Those people with direct experience in receiving services can offer a great deal of experience and wisdom in helping the Committee to focus its concerns on direct client issues. These people can provide a unique perspective and can assist the HRC in making contact with and gaining the trust of clients in the programs it monitors.

The question of who has a direct or indirect financial or administrative interest is often asked. Persons with a financial interest include employees of DMH, employees of any DMH vendor program or other people who receive money from the Department or one of its vendors. Persons with administrative interest include those who have some authority over how the Department or the

vendor manages. This includes members of the vendor's board of directors and DMH Area Board members. (Area Boards have an advisory role in the budget process.) The purpose of this provision is to assure that the HRC is sufficiently independent of the programs it monitors.

This is also what is referred to as the "one-fifth rule" meaning that only one member in five may have such interest. If the HRC has ten members then two may have such interest.

An allied health professional can include a physician, psychologist, physical therapist, occupational therapist or nurse including LPNs, RNs, Nurse Practitioners, etc. The intent of this requirement is to provide the Committee with access to relevant, professional input. It is suggested that HRCs recruit people in this category whose experience will be of value in monitoring the particular programs they oversee. If the Committee monitors day programs, then an occupational therapist with experience in designing workshop programs may be very valuable. HRCs in mental health programs are not legally obligated by the regulations to have an allied health professional, but it is strongly encouraged to give the HRC access to the relevant professional information necessary to adequately address its functions.

The requirement for a person with legal experience includes attorneys, paralegals and law students. We encourage Committees to try to recruit those people who have experience relevant to Committee's programs, i.e. mental health, special education, civil rights or disability law. Likewise, a person who has experience in mental health or retardation and is now in law school can provide relevant experience. Again, HRCs in mental health programs are not legally required to meet this standard, but it is strongly suggested. Many of the issues a Committee deals with can often be facilitated by having a person with legal experience on the HRC.

The term "advocates" is not defined in the regulations. When seeking to recruit advocates for the HRC it is encouraged that members of formal advocacy groups be used for this category. Examples of formal advocacy groups include: Associations for Retarded Citizens, Alliance for Mentally Ill, Coalition

for the Legal Rights of the Disabled, Developmental Disabilities Law Center, Mental Health Legal Advisors, and others. The intent here is to establish HRCs made up of those people with demonstrated interest in the field. The groups listed above are for the purpose of example only, the OHR and DMH do not endorse specific advocacy groups.

The HRC may add other members to the Committee as necessary, providing the "one-fifth rule" is observed. The HRC may find itself in a situation where special expertise is necessary which can only be found locally in people who have a conflict of interest. There is nothing to prohibit the HRC from using such people as regular advisors. They may not be voting members, however, without complying with the "one-fifth" rule.

The goal of these requirements on membership is to provide the HRC with a range of related experience and expertise, as well as independence, which will give it the necessary tools, the sustained interest, and the freedom to function that will allow it to carry out its duties in an effective manner. It has been our experience that those Committees with a narrow membership find themselves addressing the same issues over and over while those with more diverse, but experientially relevant, memberships are able to more successfully address a broader range of issues.

*Larry Wheeler, M.Ed., is the Director of the Office for Human Rights of the Massachusetts Department of Mental Health*

#### EDITOR'S NOTE

An invitation is hereby extended to all readers to send questions, comments, and suggestions to Vartan M. Artinian, Editor, Human Rights Newsletter, Department of Mental Health, 160 North Washington Street, Boston, MA 02114. Your views and ideas are encouraged, welcomed and needed to make the Newsletter everything it can be for Massachusetts' mentally disabled community.



## HUMAN RIGHTS CONFERENCE

The Third Annual Human Rights Conference of the Massachusetts Department of Mental Health (DMH) was held on Thursday, May 22, 1986 at the Sheraton Conference Center in Mansfield, Massachusetts. The all-day conference, entitled "Controversies in Human Rights", was jointly sponsored by DMH Office for Human Rights (OHR) and the Massachusetts Law Reform Institute. More than five hundred advocates, clients, relatives, providers and DMH staff attended the conference.

In his opening remarks, Mr. Larry Wheeler, Director of the Office for Human Rights, thanked the Conference Planning Committee (Jody Shaw, Tony Winsor, Susan Krumholz, Vartan Artinian) for their efforts in organizing the conference. As part of his introduction of Commissioner Edward M. Murphy, Mr. Wheeler noted the significant progress made by OHR within the last year since Commissioner Murphy came to the Department of Mental Health.

Commissioner Murphy commended the staff of OHR for bringing about considerable progress in the area of Human Rights. He stated that full time Human Rights Officer positions in State Hospitals and Mental Health Centers are now being filled. He reminded everyone not to lose sight of the substantial progress in Human Rights throughout the Department of Mental Health. He appreciated the commitment of individuals as expressed by their willingness to come and participate in this conference. Finally, Commissioner Murphy assured everyone that the Department of Mental Health is committed to ensure that Human Rights occupy a rightful place in the mental health system in Massachusetts.

Mr. Wheeler then introduced the Keynote Speaker, Massachusetts Senator Jack Backman, as a person who has devoted most of his life helping individuals with disabilities and supporting their rights. Senator Backman said that this conference was the largest gathering of people committed to Human Rights that he has ever attended in his career. He then related incidents and sites that his special committee had investigated and reviewed. He expressed hope that in a few years there will not be a need for gatherings

of this size to assert the rights of individuals with disabilities. A plaque from the DMH Office for Human Rights was then presented by Commissioner Murphy to Senator Backman, in recognition of a lifetime of service to the human rights of individuals with mental disorders.

The highlight of the conference was a morning panel discussion on "Aversive Therapy: What Place in Treatment?", very ably moderated by Ernest (Tony) Winsor, J.D., Staff Attorney of the Massachusetts Law Reform Institute and a member of the Conference Planning Committee. Participants in this panel were Dennis C. Russo, M.D., Director of the Behavioral Medicine Program of Children's Hospital; John McGee, Ph.D., Associate Professor, Department of Psychiatry of the University of Nebraska's School of Medicine and a renowned expert on alternatives to aversive treatment; Roderick MacLeish, Jr., J.D., an attorney representing Behavior Research Institute, which utilizes aversive techniques; and William G. Crane, J.D., Director of the Developmental Disabilities Law Center and active in efforts to halt the use of aversives in State funded programs.

Dr. Russo noted that aversives are among a potentially large number of treatment techniques to be used with developmentally disabled clients, but to be used only in certain cases, only after the less restrictive methods have failed, only when very specific guidelines are utilized. The use of aversives should be balanced with the use of a positive rehabilitative program.

Professor McGee stated that he does not use any punishment with the children and adults he serves in his program at the University of Nebraska College of Medicine in Omaha. He indicated that punishment does work if one's goal is submission. He said bonding and human interdependence should be our goals, not submission. Dr. McGee believes that through gentle teaching it is possible to turn the hate of clients with severe behavior problems to mutual love and respect.

Attorney Macleish felt that the substituted judgment procedure was the best approach to make decisions regarding the use of aversives. He said that the substituted judgment process removes the treatment decision from the state, from the proponents of a particular approach who may have a vested interest in their own methodology, and from the parents who may not have the ability or the expertise to decide in the best interest of their children.

Attorney Crane pointed out that when aversives are labeled "treatment", regardless of the level of intrusiveness or potential for abuse, a clinician is given a great deal of discretion, whether it is by a Probate Court or by a regulatory agency. The most fundamental problem has been the chronic failure of the public agencies to develop humane and effective alternatives to the highly intrusive procedures offered in certain private facilities. In conclusion, Attorney Crane emphasized that the responsible regulation of aversive procedures present important challenges to all of us to re-examine the effectiveness of our regulatory procedures and standards, because we simply cannot and should not permit our most disabled and vulnerable citizens to be abused in the name of treatment.

At lunch, awards were given to twenty individuals for outstanding achievement in furthering the rights of the mentally disabled.

In the afternoon, the conference featured ten workshops on such issues as client access to records; sexuality in DMH programs; deaf individuals in our MH/MR systems; treatment of adolescents; and community living vs. institutions.

## RELEASE OF INVESTIGATION REPORTS TO HUMAN RIGHTS COMMITTEE

By Richard Ames

Clearly, the Human Rights Committee has a right to a copy of the investigation report in any case in which it has given written notice to the person in charge that it wishes to become a party pursuant to 104 CMR 24.11(3).

In any other case involving a client who is incapable under 104 CMR 24.02, the Human Rights Committee has an obligation to "make special efforts to monitor the program's compliance with Department regulations for all such clients", 104 CMR 24.11(c). It is my opinion that in order to carry out this responsibility, the Committee should be granted access upon request to investigation reports involving incapable clients, in accordance with 104 CMR 2.07(3)(c)(3).

Determinations as to whether investigation reports regarding other clients should be released to the Human Rights Committee are made on a best interests basis, in accordance with 104 CMR 2.07(3)(c). It is generally appropriate that investigation reports be released to the Human Rights Committee on this basis, except in unusual circumstances when there are particular reasons why release to the Committee is not in the client's best interest.

Once in possession of the report, the committee holds it subject to confidentiality requirements regarding client records.

*Richard Ames, J.D., is the General Counsel of the Massachusetts Department of Mental Health*



## DISABLED PERSONS PROTECTION COMMISSION ESTABLISHED

BY Richard Howard

The most recent supplemental budget contains an outside section creating a Disabled Persons Protection Commission, but permanent authorization is still pending in the House Committee on Ways and Means. The Commission is a product of four years of work by advocates and legislative sponsors to enact legislation to respond to the problem of abuse of disabled adults. Because the enacted legislation is part of the budget, it is only effective for one year, therefore, further legislative action is necessary on S.1794 to assure a long-term solution. S.1794 now is pending in the House Ways and Means Committee, having been approved by the full Senate.

The new enactment, Chapter 279, §10, a shortened version of S.1794, was included in the budget through the efforts of Senators Patricia McGovern, Jack Backman and George Bachrach. The section establishes the Disabled Persons Protection Commission within, but "not under the control of," the Executive Office of Human Services. The Commission will consist of three persons appointed by the Governor. As of early September, those appointments have not been made. The Commission is mandated to create a system to investigate and provide protective services for disabled adults (under age 60) who are being abused and neglected. The system must include mandatory reporting of abuse and neglect, prompt investigation and arrangements for protective services for those who need it. Retaliation against any person who reports abuse and neglect is prohibited. The Commission is authorized to hire staff and contract with other agencies to fulfill its obligation.

Further information about the legislation is available from the Office for Human Rights (727-1969) or the Disability Law Center (723-8455).

*Richard Howard, J.D., is the Executive Director of the Disabilities Law Center.*

## NEW STAFF MEMBERS OF OHR

Three new members have joined the staff of the Office for Human Rights since June 1, 1986.

Joyce Collins, B.S., J.D., has assumed the position of Client Rights Coordinator once held by Bob Lashman. She was previously the Human Rights Officer at Metropolitan State Hospital, and has recently graduated from law school. Prior to coming to DMH, she worked for Massachusetts General Hospital running community and school based public health programs, several of which served disabled clients. Joyce will monitor cases, provide technical assistance and supervision to the Human Rights Officers in Mental Health facilities and work on special projects such as the Deafness Task Force.

Philomena Mare, M.S.W., has been appointed Supervisor of Human Rights Officers of Metro District Mental Health Centers. Philomena has received her Bachelor of Arts degree in Sociology from Emmanuel College. She completed graduate studies in 1980 at Boston College Graduate School of Social Work. For the past six years, she has been employed by Mass. Mental Health Center as the Mental Health Coordinator.

Esther Rosado-Sandoz is our part-time Human Rights Trainer. She is presently completing her Masters in Education, concentrating in Staff Development, at Cambridge College. New to the mental health field, Esther has been working three years as a Hearing Officer/Consumer Coordinator for the State's Department of Public Utilities.

## **FULL TIME HRO'S AT STATE HOSPITALS**

As Commissioner Edward M. Murphy announced at our Third Annual Human Rights Conference on May 22, 1986, the full time Human Rights Officer positions in State Hospitals are now filled. They are: Stephen Wall, Northampton State Hospital; Antoinette Raymond, Worcester State Hospital; Robert Foster, Danvers State Hospital; Michael Kemp, Metropolitan State Hospital; Doug Richard, Medfield State Hospital; Mae Young Cho, Westborough State Hospital; and Karen Viveiros, Taunton State Hospital.

Pursuant to DMH Policy #85-8, all Human Rights Officers at State Hospitals, State Schools and Community Mental Health Centers are supervised by the Office for Human Rights.

## **SPECIAL THANKS**

Special thanks are extended to Ms. Moreen Durham, Administrative Assistant here at the Central Office of DMH, for her aid in the preparation of this issue of the Newsletter. Also, a special note of gratitude to Mr. Martin Rachels, Human Rights Officer at Belchertown State School, for tape recording and partially transcribing the proceedings of the morning panel discussion on "Aversive Therapy" of our Third Annual Human Rights Conference.

**OFFICE FOR HUMAN RIGHTS  
MASS. DEPT. OF MENTAL HEALTH  
160 NORTH WASHINGTON STREET  
BOSTON, MA 02114**





# HUMAN RIGHTS NEWSLETTER

Vol. III, No. 1

October 1987

## COMMISSIONER MCCARTHY ADDRESSES HUMAN RIGHTS CONFERENCE

The Fourth Annual Human Rights Conference of the Massachusetts Department of Mental Health was held on Friday, May 29, 1987 at the Sheraton Conference Center in Boxborough, Massachusetts. More than six hundred advocates, clients, relatives, providers, and Department of Mental Health staff attended the Conference. The keynote address was delivered by Mary A. McCarthy, first Commissioner of the new Department of Mental Retardation. Here are excerpts from that address:

"When an annual Human Rights Conference can draw over 600 individuals from around the Commonwealth and some from other states as well, I think it is not only a tribute but an enormously exciting time that we have renewed and have continued to maintain the intensity and tenacity of the importance of the issue of human rights and client dignity.

I was asked today to provide to you the welcome for this Fourth Annual Conference which is my great honor and privilege to do so. The fact that there could have been three previous to this and a fourth, and undoubtedly a fifth and then on in the future years, not only for the Department of Mental Health but most assuredly as well for the Department of Mental Retardation, stands further as tall a tribute to the importance of this question and dedication of all you to these questions. So let me on behalf of both these agencies, I am sure Commissioner Murphy will not mind, welcome you to the Fourth Annual Human Rights Conference.

As a system, as two systems now, we not only urge your active debate of the issues that you will confront today, but we rely upon them. You will seek balances which protect rights and provide help. You will weigh freedom and responsibility, privacy and intervention, self-determination and prescription, benefit and risk. Ramifications of these questions touch the very heart of our services and the people that we serve. The debates must therefore be intense, honest, sensitive, and thoughtful, for we tread on the most sacred of territories: quality of life, choice, treatment, service, freedom.

To what extent should different segments of government intervene? Where are the clinical vs. the judicial lines? Who decides and how? How do we best serve and best protect those who cannot speak for themselves? These issues are ones that do not have easy or simplistic answers. These are some of the kinds of things we will confront day in and day out and that all of you will confront day in and day out. That is the beginning of the spectrum and it only gets increasingly more complex as we tackle issues.

In the development of a new department, we will seek to carry on the traditions and prophesies employed in the current human rights system. An office for Human Rights will absolutely be established at the Commissioner's level and will be responsible for overseeing human rights efforts throughout the orga-

---

Published by the Office for Human Rights, Massachusetts Department of Mental Health and Department of Mental Retardation, Robert J. Foster, Interim Director; Vartan H. Artinian, Editor, 160 North Washington Street, Boston, MA 02114 (617) 727-9844.

nization, at the regional level, at the local service center level, and in our facilities.

In our vigilance on the issue of client rights and dignity we must extend ourselves and reach into the daily operations of our services, into the quality assurance and licensing standards we set into our regulations, into our policies, and daily activities and procedures. We welcome your assistance in shaping such a system. We are grateful for your time, for your thoughts, for your interest both today and over the years.

The proceedings from this conference will be useful to an intricate organization, especially beginning approximately a month from today, and

try to set the sights on making certain that we protect, ensure, and promote client dignity and freedom. Let me simply say then, we welcome you to today's conference. I know that you will find, as I did, that the various panels and workshops that you will attend throughout the course of the day will be not only thought provoking, but will really reach to the heart of the matters which we have all wrestled rather intensively over the years and will probably continue to do so.

Thank you for your participation, I wish you a successful conference and look forward to continuing to work with you in a variety of fashions as the Department of Mental Retardation begins to take shape in a way that shows a very strong commitment in protection of human rights of our clients."

## 1988 ANNUAL HUMAN RIGHTS CONFERENCE

As a result of the division of DMH into two agencies, there will be two separate Human Rights Conferences during the fiscal year 1988.

The Annual Human Rights Conference of the new Department of Mental Retardation will be held on Friday, April 29, 1988, and the Annual Conference of the Department of Mental Health will take place on Friday, May 6, 1988. Each conference will be sponsored jointly by the Office for Human Rights and the Massachusetts Law Reform Institute. Both conferences will be held at the Best Western Royal Plaza Hotel in Marlborough, Massachusetts.

These conferences are designed to bring staff, clients, Human Rights Officers, advocates, Human Rights Committee members, and other individuals interested in Human Rights together in a forum. An invitation is hereby extended to all interested individuals to send in their suggestions, ideas, comments, and issues that they would like to be considered at the Conferences. Also, summaries of potential presentations for both conferences are encouraged and welcomed. Please send your views and materials by December 1, 1987 to:

Conference Planning  
Committee  
Office for Human Rights  
Dept. of Mental Health  
160 North Washington St.  
Boston, MA 02114



## SUBSTITUTED JUDGEMENT

By Robert J. Foster

A 45 year old man was admitted to the inpatient unit where I was working a number of years ago. His record indicated that he had been living with his parents until his admission to the unit. He had many skills but he did not shave himself.

The inpatient staff, a young group of people, believed that part of their job was to keep clients informed of the styles and fashions that were in vogue. They decided that this man should have a moustache. About a week later, his mother came in to visit. She saw her son and became very upset and immediately shaved off the man's moustache. To the staff, the man looked good and it was part of the normalization process. To the mother, who followed more traditional values, he looked unkempt, and perhaps a bit of a rogue. The man expressed no preference. He enjoyed being shaved. So the fact that both the staff and his mother shaved him was just fine.

What would the client have decided if he were able? Would he have followed the social norms, or the more traditional family values?

Over 600 people came together at the Sheraton in Foxborough, Massachusetts on May 29, 1987 to discuss "Who decides when the client can't?", the concept of Substituted Judgement.

Substituted judgement means that an individual makes a decision for another individual by taking into account what they would have decided if they had been able. To go back to the example earlier, a person would have made the decision whether or not the man should have a moustache not by the standards used

by either the staff or the mother, but by using the man's own criteria. Since 1983, when the court decided the case, Roger's v. Commissioner of Mental Health, the judge must use substituted judgement when deciding an extraordinary treatment case. The court has designated these to be antipsychotic medication, sterilization, withholding of life prolonging treatment, chemotherapy or electroconvulsive shock treatment (ECT). When making a substituted judgement six factors must be taken into account. First, the judge will consider the person's expressed preferences regarding treatment. These may be things the person said when competent in the past as well as what is being expressed at the time of the hearing. Second, the person's religious convictions will be considered, especially if the person's religion forbids medical treatment. The impact on the person's family must be included as a factor. Would treatment be a benefit or detriment to the family relationship? What side effect, if any, may result from treatment? Their level of probability, and seriousness must be weighed. The alternatives and their effects must also be examined. Finally, the prognosis must be considered.

This concept, which is unique to Massachusetts, was the topic for the morning panel at the spring conference. Jody Shaw moderated a panel of experts with differing opinions on substituted judgement. In the next issues, we will be reporting on this panel as well as the content of some of afternoon presentations.

The moustache was perhaps a trivial matter. But the concept becomes more important when deciding matters that may irreversibly effect the lives of individuals.

Robert J. Foster, M.Ed., M.S.W., is the Interim Director of the Office for Human Rights of the Massachusetts Department of Mental Health and the Department of Mental Retardation.

## COMPETENCY

By Stan Goldman

While it is easy to talk about competency and informed consent in a general way, it is much more difficult to then apply these concepts to specific cases. In all cases, however, the ultimate question is: does the person have the ability to make an informed decision with respect to the situation presented?

To answer this question, two determinations must be made: first, the patient's capacity to understand information pertinent to the treatment proposed must be evaluated. That is, you must assess his/her ability to understand what the particular problem is; what the proposed treatment is likely to do; what risks may be involved in undergoing that treatment (i.e. what are the possible side effects); what is the probability that any of these effects will occur and, if they occur, what is the severity likely to be of any particular side effect; what other treatment modalities are available, if any, and, again, what are the likely benefits and the likely side effects of these alternative treatments; and, finally why it is that you are selecting the prescribed treatment rather than the other possible alternatives.

Next, you must assess the person's ability to take that information, assimilate it, and make a reasoned decision whether or not to accept the proposed treatment. It is important to understand, however, that when I say "a reasoned decision", I'm speaking of the reasoning process relied upon to make a decision, not merely what that decision happens to be. As you know, a patient has the right to refuse treatment as long as the refusal is based upon competent reasoning ability. Furthermore, we must keep in mind that a person has a right to make "bad" choices and that bad choices don't necessarily indicate incompetency.

Let me give you an example. We know that there is a very high likelihood that smoking cigarettes is somehow related to a number of things that most people would not like to happen to them. That doesn't mean, however, that everyone who chooses to smoke cigarettes is incompetent. It usually only means that he/she is making a "bad" choice and we all have the right to do so. What you have to prove to the judge in a guardianship hearing is that the person is so impaired by mental illness that he/she is either not able to sufficiently understand pertinent information or is not able to use a reasoned decision-making process, based in reality, in arriving at his/her choices.

Another important aspect of competency is that the capacity to make a reasoned decision depends very much upon the particular situation presented. Again, let's use a medical example. It appears reasonable to distinguish between the kind of reasoning ability necessary to make an informed choice as to whether or not to take aspirin for a headache and that necessary to decide whether or not to undergo surgery. Somebody who might not be competent to consent to surgery may be quite competent to make a decision about something as relatively innocuous as taking an aspirin for a headache. The complexity of the medical problem or of the proposed treatment will determine the complexity of the decision-making process necessary. Somebody may be competent in one area and incompetent in another; you must determine in each particular case what the reasoning ability of the person is relative to the complexity of the decision that must be made.

The typical guardianship case involves decision-making in respect



to medical treatment that is relatively routine and not particularly intrusive or unusual. When such usual, or "nonextraordinary" kinds of treatment are involved, the judge, after finding the person incompetent, has to determine what is in the person's best interest. In other words, what is medically indicated.

In the case of "extraordinary" care, and specifically where antipsychotics are involved, the judge must determine what the person would decide, if competent (i.e. the judge must determine the person's "substituted judgment"). However, there are some situations in which such prior court authorization is not necessary. Where the person's behavior poses a threat of serious physical harm or violence, he/she may be medicated in accordance with the Department's Restraint and Seclusion Regulations. Similarly, where an incompetent person's refusal to permit the administration of antipsychotics would lead to a "substantial, immediate and irreversible deterioration of his/her mental health", the medication may

be administered. Please note that this second exception pertains only to an incompetent person - a competent person may refuse treatment even if the refusal would lead to such a deterioration. Also note that despite the authority to medicate in this second situation, a guardianship (Rogers) order must still be sought as soon as practicable.

In summary, to assess a person's "competency" (i.e. his/her ability to make an informed decision), you must determine the following: does the person have the ability to understand information pertinent to making that decision, and, if so, can he or she then assimilate that information and make a reasoned choice? The choice doesn't necessarily have to be the one with which you would agree; we have a right to make bad choices. Competency varies from decision-making situation to decision-making situation; some people can be competent in one area and not competent in others. What the judge ultimately has to decide in every case, is in what areas of decision-making does that person need assistance.

#### HUMAN RIGHTS AWARDS RECIPIENTS

At our Fourth Annual Human Rights Conference on May 29, 1987, Human Rights Awards were presented to five individuals who had made contributions to the human rights of Department of Mental health clients.

The award recipients are:

LARRY WHEELER, former Director of the DMH Office for Human Rights, for his extraordinary contribution to protecting the human rights of DMH clients. Mr. Wheeler's award was presented by Mary A. McCarthy, Commissioner of the Department of Mental Retardation.

RICHARD HOWARD, Director of the Disability Law Center, for spear-heading enactment of the legislation creating the Disabled Person's Protection Commission.

IRIS CARROLL, Director of Framingham Day Hospital, for her exceptional service in establishing therapeutic therapy for the emotionally handicapped.

DARCEY OLIVEIRA PERRY of Fall River, Executive Director of Adsum Inc., for providing independent living programs for the mentally retarded.

PAUL MOMBOURQUETTE, a DMH health coordinator, for facilitating community placement of the Monson Developmental Center clients.

## "WHAT SHOULD YOU DO?"

By Sara Wright

Imagine, if you will, the following incident:

It is Tuesday morning and you are on your second day at work in a group home for retarded people. It is the middle of the morning and Ted, one of the clients, starts to reach for a cup of coffee that a staff member left behind. You know Ted shouldn't have coffee, he's hyper enough as it is, but before you can get over to him your supervisor intervenes. She takes the cup of coffee, saying, "You know you cannot have that, Teddy." He tries to take it back and a struggle ensues and finally your supervisor cuffs him on the ear hard enough to send him sprawling on the floor. Your face must show the shock you feel because your supervisor says, "You have to treat Teddy that way, its the only thing he understands. Come on, Teddy, get up off the floor."

The preceding fictitious incident is the introduction to a new video tape titled "What Should You Do?" The tape was created at a state hospital to inform employees of what they should do if they have "reasonable cause to believe" that a disabled person has been abused.

The tape was designed to train staff of their obligations under the Disabled Persons Protection Act (DPPA), and to teach them in more general ways about abuse, about their responsibility to help protect their patients from it, and their responsibility to report it, should it occur.

Developed at Danvers State Hospital by Sara Wright, Human Rights Officer, and Reggie Silberberg, Training Program Coordinator, "What Should You Do?" employs fictitious instances as well as didactic presentation to accomplish these goals. Obligations under the DPPA as well as under the investigation regulations are spelled out in detail. Care is taken to explain what is meant by "dangerous, illegal and inhumane incidents and conditions" with the intention of raising the sensitivity of care givers themselves, as well as informing them of legal obligations. It is hoped that this is a step towards making the concerns of human rights more understandable to direct care staff.

Copies of the tape may be obtained on loan from Vartan Artinian, Office for Human Rights in Central Office, 160 North Washington St., Boston, MA 02114, Tel: (617) 727-9844. It lasts approximately fifteen minutes and is available for use whenever audiences need further information on the DPPA, the complaint procedure, and reporting abuse.

Sara Wright, Ed.M., M.Div., is the Human Rights Officer at Danvers State Hospital.

### EDITOR'S NOTE

This Newsletter is published primarily for Human Rights Committees (HRCs) and Human Rights Officers (HROs) of the Massachusetts Department of Mental Health and the Department of Mental Retardation. If you know of HRCs or HROs who are not receiving the Newsletter, or have questions, comments, and suggestions concerning what should be included in future issues, please contact Vartan H. Artinian, Editor, Human Rights Newsletter, Department of Mental Health, 160 North Washington Street, Boston, MA 02114. Your views and ideas are encouraged, welcomed, and needed to make the Newsletter everything it can be for Massachusetts' mentally disabled community.



REGIONAL TRAININGS FOR COMMUNITY HRO'S & HRC'S

The Office for Human Rights is planning training sessions for community program Human Rights Officers and Human Rights Committees. A training session will be held in each Region sometime in the next few months. In order to be able to better plan for these trainings, please complete the questions listed below and mail your answers to:

Vartan Artinian  
Office for Human Rights  
Department of Mental Health  
160 No. Washington St.  
Boston, MA 02114

Yes, I am interested in attending the Human Rights training.

NAME: \_\_\_\_\_

ADDRESS: \_\_\_\_\_  
\_\_\_\_\_

PROGRAM/NAME: \_\_\_\_\_

ADDRESS: \_\_\_\_\_

I am a (a) community program designated HRO \_\_\_\_\_  
(b) Human rights committee member \_\_\_\_\_

I would prefer to attend the training:

\_\_\_\_\_ 1. Two consecutive week nights (3 hours each)

My choice of week nights are \_\_\_\_\_ and \_\_\_\_\_  
nights. (Monday, Tuesday, etc.)

\_\_\_\_\_ 2. One full day on the weekend (6 hours)

My choice of a weekend day is \_\_\_\_\_  
(Saturday or Sunday)

I have had prior human rights training: yes \_\_\_\_\_  
no \_\_\_\_\_

If yes, who conducted the training? \_\_\_\_\_  
When was this training given? \_\_\_\_\_

I would like the training to cover the following topics:

## RECEPTION FOR ADVISORY COMMITTEE TO OFFICE FOR HUMAN RIGHTS

A special reception was jointly given by DMH and DMR to the members of the Advisory Committee to the Office for Human Rights on September 2, 1987 at the Conference Room of the Department of Mental Retardation.

Following the opening remarks by Robert J. Foster, Interim Director of the Office for Human Rights, Mary A. McCarthy, Commissioner of the Department of Mental Retardation, and Dr. Henry Tomes, Deputy Commissioner for Mental Health Services, representing Commissioner Edward M. Murphy, thanked the members of the Advisory Committee for their dedicated service to both Departments.

Each member of the Advisory Committee was presented a special plaque by Commissioner McCarthy, in appreciation of his/her voluntary service on the Committee from February 1985 to September 1987. Here are the names of the recipients of the plaques: Chairman David Engle, Vice Chairman Herbert Lovett, Secretary Jody Shaw, David Bunker, Joseph Carson, William Crane, Barbara Cutler, Nona Dearth, Amy Durland, Robert J. Foster, Mark J. Hauser, Diane M. Iagulli, Victoria M. Johnson, Lewis B. Klebanoff, Phyllis Nobel, Lenore Levin Piper, Ruth C. Snider, Dorothy Elizabeth Tucker, Gloria Werman, Ernest Winsor.

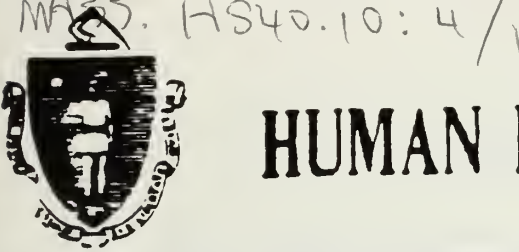
## COMMUNITY HRO CERTIFICATION TRAININGS

The Office for Human Rights will be offering regular monthly trainings for our Human Rights Officers in community programs. These trainings are designed to assist the community Human Rights Officers in addressing their functions and implementing their responsibilities as effectively as possible. Participating Human Rights Officers will receive special certifications for their attendance.

These training sessions will be held in Worcester, Massachusetts on the second Wednesday afternoon of every month. The first session will take place on Wednesday, December 9, 1987, 1:30 - 4:00 p.m.

Participation is by registration only. Interested community Human Rights Officers are requested to register by contacting the Office for Human Rights, 160 North Washington Street, Boston, MA 02114. Telephone: (617) 727-9843.





# HUMAN RIGHTS NEWSLETTER

Vol. IV, No. I

March 1988

## OHR PLANS FOR SPLIT

As split of the Department of Mental Retardation and the Department of Mental Health progresses, the Office for Human Rights has begun to formulate plans for the future. There will be two separate Offices for Human Rights, one for the Department of Mental Health and one for the Department of Mental Retardation. The Department of Mental Health Human Rights Office will be staffed by a Director, a Human Rights Specialist, a Human Rights Officer Coordinator, a secretary based in Central Office and one Human Rights Officer based in each of the seven state hospitals. A Director and two staff at Central Office, and Human Rights Officers based in each of the eight facilities will comprise the Office for Human Rights of the Department of Mental Retardation. Unlike the past, all positions are full time state positions.

Since the implementation of the DMH Policy that formed the Office for Human Rights in 1985, that Office has experienced a growth of resources and staff. In the first year of operation, a Director, four full time, and one half time consultants were identified to establish the Office. In the second year, seven new positions were secured to be used as full time Human Rights Officers in the State Hospitals. During the third year, the eight Human Rights Officers in the State Schools were transferred to the Office for Human Rights.

The Central Office for the Department of Mental Health will be staffed by Robert J. Foster, Director, Vartan H. Artinian, Human Rights Specialist, and a Human Rights Officer Coordinator. Jean E. Tuller will direct the Office for the Department of Mental Retardation. Joining her will be a Human Rights Specialist in addition to Philomena Hare who had been the HRO Supervisor for Region VI.

---

Published by the Office for Human Rights , Massachusetts Department of Mental Health and Department of Mental Retardation. Robert J. Foster, Director; Vartan H. Artinian, Editor, 160 North Washington Street, Boston, MA 02114 (617) 727-5858.

## ROBERT J. FOSTER APPOINTED DIRECTOR OF OHR

On January 7, 1988, Edward M. Murphy, Commissioner of the Department of Mental Health, announced the appointment of Robert J. Foster to the position of Director of the Office for Human Rights. "As you know," stated the Commissioner, "Bob has been with the Office for Human Rights since August of 1986; first at Danvers State Hospital and, more recently, as Interim Director."

Mr. Foster has received his B.A. in Psychology from Southeastern Massachusetts University, M.Ed. in Counseling from Northeastern University, and M.S.W. in Administration from George Warren Brown School of Social Work of Washington University in St. Louis, Missouri.

Mr. Foster has extensive experience in the field of mental health. During the past sixteen years, he has worked as Consulting Psychologist at Wrentham State School; as Human Rights Officer and Mental Health Coordinator at Corrigan Mental Health Center; as Director of Operations at Vocational Counseling and Rehabilitation Services in St. Louis, Missouri, where he also wrote a clients rights and complaint policy; as Director of Continuing Care and Affirmative Action Officer at Lower Cape Human Services; as Instructor at Cape Counseling Center in Hyannis where he provided group and individual substance abuse counseling to adults.

Between 1985 and 1987, Mr. Foster was one of the founding members and the Vice Chairman of the Advisory Committee to the Office for Human Rights of the Department of Mental Health. He was the principal formulator of the By-Laws of this Committee, and the Chairman of its Training sub-committee which was responsible for advising the Office for Human Rights on the preparation of materials for all types of training.

Mr. Foster states that he plans to continue the work of the Office for Human Rights in the State Hospitals and move to provide support and guidance to the network of Human Rights Officers in the Community Programs. "The Human Rights network," said Mr. Foster, "must begin to see itself as one entity, learning and growing from one another's experiences. We need to develop mechanisms that will provide the necessary information and advocacy so that we may enhance the rights protection of people receiving services throughout the Department of Mental Health."

The Staff members of the Office for Human Rights join Commissioner Murphy in welcoming Bob to his new role and wish him continued success.



## THE DOCTRINE OF SUBSTITUTED JUDGMENT

The Fourth Annual Human Rights Conference of the Massachusetts Department of Mental Health took place on May 29, 1987 at the Sheraton Conference Center in Boxborough, Massachusetts. More than six hundred clients, relatives, advocates, providers, and DMH staff attended the all-day conference which was jointly sponsored by the DMH Office for Human Rights and the Massachusetts Law Reform Institute.

The highlight of the conference was a morning panel discussion on "WHO DECIDES WHEN THE CLIENT CAN'T?", moderated by Jody Shaw, J.D., Executive Director of the Massachusetts Developmental Disabilities Council. The four presenters of the panel were Robert Fleischner, J.D., Assistant Director, Center for Public Representation; Laura Monroe, J.D., Staff Attorney, greater Boston Elderly Legal Services; Michael B. Roitman, J.D., Staff Attorney, Fine & Ambrogne; Ernest Winsor, J.D., Staff Attorney, Massachusetts Law Reform Institute. The three responders were Jack Backman J.D., Former State Senator; Charles Baron, J.D., Ph.D., Professor of Law, Boston College Law School; Steven K. Hoge, M.D., Director, Forensic Evaluation Clinic, University of Massachusetts Medical Center.

In her introductory remarks, Jody Shaw stated that there are probably tens of thousands of persons in our Commonwealth who, by virtue of some kind of mental disability, may not be in a position to make intelligent, cognitive choices about very important matters in their lives. Massachusetts is known as the "Substituted Judgment State," since numerous such determinations about important life decisions for individuals with mental disabilities are made, over the last fifteen years, by judges following various proceedings in a court of law. Ms. Shaw expressed hope that by the end of the session, participants will have a clear notion of what the substituted judgement doctrine means in Massachusetts, how it works, and how a number of people feel about this doctrine as it can or may be applied in a fairly wide range of decision making situations.

The first panelist was Attorney Robert Fleischer who has represented people in over fifty substituted judgment cases that have involved antipsychotic medication, electro-convulsive therapy, sterilization, abortion, extraction of all teeth, the use of general anesthesia, and several different kinds of medical interventions. In his presentation, Mr. Fleischner took a look at the substituted judgment doctrine both on its theoretical and practical levels. He felt that the concept of substituted judgment seems to be a good idea to protect the exercise of a person's rights with another person exercising them when the person who should be exercising them can't because of incapacity. However, Mr. Fleischer suggested that there are some rights that clearly are not able to be exercised by others. He seriously questioned the workability of the application through substituted judgment of the right to free speech, the right to vote, and the right to

accept or refuse certain treatment interventions. He then cited the most important case in Massachusetts, the case involving a mentally retarded man who had leukemia and the treatments available for him could have prolonged his life. The Probate Court Judge applied a substituted judgment termination doctrine and decided that the client, if he were competent and if he understood that he was incompetent, would not accept the treatment and that he would therefore die. The decision was upheld by the Massachusetts Supreme Judicial Court and, in the interim, the client died without the treatment. Mr. Fleischner pointed out that it is impossible for people who are not disabled to understand how disabled persons feel about their disability. He concluded that basically the substituted judgment doctrine is dishonest, and what happens in most cases is the best interest determination.

The second presenter was Laura Monroe who has been active as a civil rights attorney to the American Civil Liberties Union since 1952. Ms. Monroe's ideas on the substituted judgment doctrine have been formed through her life experiences. She stated that she spent the first 14 years of her life running away from the Nazis and developed a deep mistrust of state power to regulate the intimate portions of one's life. Moreover, her mother, her father, and her husband all died of cancer contributing heavily to her lack of confidence in physicians. She expressed strong belief in the living will and euthanasia. She said that human beings should be able to control their own bodies, and judges, as arms of the state, are not good substitutes for this purpose.

The third panelist was Attorney Michael B. Roitman who was co-counsel, recently, for the private school, Behavior Research Institute, in the Massachusetts Probate Court proceedings which resulted in a determination of substituted judgment and the standards to be applied in decisions relating to intrusive and aversive therapy. Mr. Roitman felt that the substituted judgment concept is a good doctrine. It may not be the best, but it certainly is better than any of the alternatives. He emphasized that in substituted judgment cases what is to be decided is not what is best for a particular client. What must be decided is not what we think is best or what a Human Rights Committee thinks is best. What is best is what the clients would have wanted were they competent. Mr. Roitman pointed out that the views of family members, Human Rights Committees, the Department of Mental Health, the Department of Mental Retardation and others should be heard, but the Court is uniquely qualified to make the final decision preserving the client's choice and dignity.

The last panelist was Ernest Winsor, a staff Attorney at Massachusetts Law Reform Institute, whose specialties include Massachusetts Civil, Administrative and Health procedures, disability law, private pleas and public record, court ordinances, and justice system structure and reform. Mr. Winsor was one of the principal designers of this plenary session. Like Mr. Roitman, Attorney Winsor supported the substituted judgment doctrine. He



pointed out that the basic notion in deciding these issues is that the decider must try to put himself into the person, into the shoes of the incompetent person and look at the situation from the point of view of the incompetent person, looking into the past, looking into the future, and trying to decide what the incompetent person wants to do. Mr. Winsor then made mention of several cases. A man who had been competent most of his life, developed kidney disease and started to develop senility. He was getting the treatment for the kidney disease, the dialysis, which was extremely intrusive and painful. The Court, through the substituted judgment doctrine, came to the conclusion that the treatment was to end and that the man's judgment would be that he would rather just die. Another case involved a retarded woman who was sexually active, and the question came up whether she should be sterilized. The Court, through the substituted judgment doctrine, decided that she, given all of the facts of her life, knowing her sexual activity in the past and knowing it in the future, would probably decide that sterilization was the best thing for her. Another case was about a man who was quadriplegic, a Vietnam veteran, who was living in pain in a hospital bed, and who didn't want to put up with it any more and he wanted to die. He just couldn't reach out to take pills that he thought might kill him. He needed somebody to help him to death. That is what euthanasia meant to Mr. Winsor who strongly expressed his belief in the right to suicide and in the right to help others to suicide.

The formal presentation by the four panelists was followed by comments from three responders. Former Massachusetts State Senator, Jack Backman, stated that in order to be excused from civil or criminal liability, it is advisable to go to court for substituted judgments.

Professor Charles Baron of Boston College Law School noted that if we are going to protect ourselves against decision making by doctors in a situation where the patient cannot make the decision for himself, we need the doctrine of substituted judgment.

Dr. Steven K. Hoge of University of Massachusetts Medical Center expressed concerns that if we continue to allow important decisions like medical treatment and sustaining lives to be taken out of doctors' hands, out of the hands of family members, then we are going to come to a point in this country where all important decisions are going to be made by the State, and there is going to be no ethical or moral decision making in psychiatric and medical study.

#### SPECIAL THANKS

Special thanks are extended to Mr. Martin Rachels, Human Rights Officer at Belchertown State School, and to Amy Wojcik, Administrative Assistant at Belchertown State School, for tape recording and transcribing the entire proceedings of the morning panel of the Fourth Annual Human Rights Conference on May 29, 1987 at the Sheraton Conference Center in Boxborough, Massachusetts.

## FIRST MEETING OF HUMAN RIGHTS ADVISORY COMMITTEES

The first joint meeting of the Human Rights Advisory Committees of both the Department of Mental Health and the Department of Mental Retardation was held on Monday, November 9, 1987 at the 21st floor Conference Room of John McCormack Building, One Ashburton Place, Boston.

The meeting was called to order at 2:30 p.m. by Robert Foster, Interim Director of the Office for Human Rights, who welcomed the guests and the members of the Human Rights Committees and invited Edward Murphy, Commissioner of the Department of Mental Health, to address the meeting.

Commissioner Murphy thanked those who had served on the previous Advisory Committee and had accepted his appointments to continue to serve on the current MH Committee, and those who joined the Committee for the first time. He assured everyone that Human Rights will continue to occupy its rightful place in the Mental Health system in Massachusetts, and asked the Committee to provide him with input and a short list of high priority items concerning Human Rights issues. Commissioner Murphy announced his appointment of Keith Rawlins as temporary Chairman of the MH Human Rights Advisory Committee until such time as the Committee elects its permanent officers. He then introduced Philip Johnston, Secretary of the Executive Office of Human Services.

Secretary Johnston stated that his office is committed to the protection of individuals with mental disabilities from all types of abuse. In addition to self-monitoring, Secretary Johnston emphasized the importance of the role of citizen advisory groups for both the Department of Mental Health and the Department of Mental Retardation in assuring the protection of the Human Rights of mentally ill and mentally retarded clients. He thanked the members of both committees for accepting their appointments and wished them success.

Mary McCarthy, Commissioner of the Department of Mental Retardation, was introduced to the group by Secretary Johnston. Commissioner McCarthy expressed her commitment to carry on the traditions employed in the current human rights system. She appreciated the commitment of the members of the MR Human Rights Advisory Committee as expressed by their willingness to serve on the Committee. She asked for their input on all matters concerning the human rights of our mentally retarded clients.

The oath of office was administered for the members of both Committees by Commissioners to Qualify Public Officers, Dorothy McLaughlin and Eileen Constantakes, from the Office of the Secretary of State.

The individuals who took the oath of office to serve on the Human Rights Advisory Committee of the Department of Mental Health were: Kevin Cahill, Iris Carroll, Joseph Carson, Gaston Cloutier, Rose



Coppinger, Amy Durland, Suzanne Ford, Mark Hauser, Lilo McMillan, Phyllis Nobel, Jacinto Raposo, Keith Rawlins, and Ernest Winsor. Gloria Werman took the oath of office at a later date.

The persons taking the oath of office to serve on the Human Rights Advisory Committee of the Department of Mental Retardation were: Jerome Bass, Bernard Brookes, Barbara Cutler, Matthew Engel, Florence Finkel, Abraham Horowitz, John Lancz, Linda Loving, Edwin Mikkelsen, Maureen O'Reilly, Lenore Piper, Gary Seltzer, Ruth Snider, Robert Sovner, and Alice Van Dusen.

#### COMMUNITY HRO CERTIFICATION TRAININGS

The Office for Human Rights has been offering certification training for Human Rights Officers in Community Programs. This training is designed to provide the basic information and skills necessary to carry out the duties of Human Rights Officers.

In June 1988, this training will take place monthly, on a Wednesday, and will start at 10:00 a.m. and end at 4:00 p.m. Participation is by registration only. Interested Community Human Rights Officers are requested to register by contacting the Office for Human Rights, 160 North Washington Street, Boston, MA 02114. Telephone: (617) 727-5858.

#### NEW LOCATIONS AND TELEPHONE NUMBERS

The Office for Human Rights of the Department of Mental Health is now located at the 4th Floor of 160 North Washington Street, Boston, MA 02114. Our new telephone numbers are: (617) 727-5857, 727-5858, 727-5859.

The Office for Human Rights of the Department of Mental Retardation is situated at the 5th Floor of 160 North Washington Street, Boston, and the telephone number is: (617) 727-5608.

#### Annual Human Rights Awards

Deadline Extended  
to  
April 8, 1988

The deadline for nominating individuals to receive the 1988 Annual Human Rights Awards has been extended to April 8, 1988. People wishing to nominate individuals should call the Office for Human Rights at (617) 727-5858.

**HUMAN RIGHTS TRAINING  
FOR FAMILIES, GUARDIANS AND FRIENDS  
By Karen Stevens**

Gail Brown, Director of Residential Services at Hampden County Association for the Retarded, is responsible for planting the seed of developing a human rights training program for families, guardians and friends of the people we serve. Our agency has long had a strong and vital commitment to human rights: we have a very active human rights committee, and comprehensive, on-going training programs for both consumers and staff. We currently have on staff three human rights representatives (officers). So this effort represented yet another important step in the process of protecting and promoting the human rights of persons with disabilities. It represented a desire to reach out to the significant people - families, guardians and friends - in the lives of consumers, and involve them as fellow team members in helping consumers exercise their rights freely and responsibly. We wanted them to understand the rationale behind our concern for human rights, and some of the complicated issues that emerge in our attempts to protect and promote these rights.

In the fall of 1986, a task force was developed to address this issue of developing a suitable training program. This group consisted of the human rights representatives, a biological parent of one of our consumers, a program supervisor and a human rights committee member who was also a consumer. The task force met on a monthly basis to design the process and content of the program. Much of the content was similar to that of our other human rights training efforts, but the emphasis was on the impact of consumers exercising their rights on the roles and relationships among family members, guardians, friends, staff and consumers. It seemed critical to explore this if we were to all work effectively together as a team. The design included our definition of human rights, roles and procedures for protecting/promoting these and a series of situations that addressed relationships to be explored. Once the session was developed, it was discussed with the management staff of Residential Services and plans were made to schedule our first program.

Our first effort to present this program was in March 1987 for families, guardians and friends of consumers in our Springfield programs. Though the group was small, we were very pleased with the response of the participants. They were open, friendly, cooperative and pretty sophisticated in their understanding of what we were trying to accomplish. Our agenda was as follows:

- Introductions and discussion of any special interests or issues that brought us here (these were noted on newsprint as a reminder).
- Presentation of a definition of human rights i.e., rules that attempt to provide all people, regardless of race, creed, sex, age, religion or degree of disability, with equal opportunities to lead lives of dignity.



- Large group brainstorming of rights we all share; this was contrasted with the specific rights individuals with developmental disabilities as listed in the "What Are Your Rights?" handbook.
- Case study analysis of possible rights violations.
- Distribution of a "who's who" list of people to contact if violation should occur or if we feel that there are rights we could be promoting more actively.
- Discussion of procedures to follow to optimize results.
- Small group discussion of situations that involve a variety of human rights team members, how these might be resolved and the implications for the relationships of among the team members. The session ran 2 - 2 1/2 hours with a 15 minute break.

This design worked well, and we felt confident that with appropriate modifications to address issues of concern at particular sites the training would be successful. With these adjustments we presented this program to family members at one of our Westfield Area sites, and plans are currently underway to do so again at another site after the first of the year.

Karen Stevens, M.S.P.H., and a Doctoral candidate in Adult Education at Columbia University, is the Education Specialist and Human Rights Representative at Hampden County Association for the Retarded in Springfield, Massachusetts.

#### VIDEO TAPE AVAILABLE AT OHR

A video tape that informs employees of public and private agencies, providing services to the disabled, of what they should do if they have "reasonable cause to believe" that a disabled person has been abused, is available at our Office for Human Rights.

The tape is designed to train staff of their obligations under the Disabled Persons Protection Commission (DPPC) and the DMH/DMR Investigations Regulations, and to teach them in more general ways about abuse, about their responsibility to help protect their patients from it, and their responsibility to report it.

Developed by Sara Wright and Reggie Silberberg, the tape, which lasts approximately fifteen minutes, may be obtained on loan from Vartan Artinian, Office for Human Rights in the Central Office, 160 North Washington Street, Boston, MA 02114, Tel: (617) 727-5858.

# **FIFTH ANNUAL HUMAN RIGHTS CONFERENCE**

**"Don't call me looney!"**

**Sponsored by  
Department of Mental Health  
and  
Massachusetts Law Reform Institute**

**Friday, May 6, 1988, 8:30 am to 4:30 pm  
Royal Plaza Hotel, Marlborough, Massachusetts**

**For advanced registration send a check for \$30.00 payable to MLRI to: Office for Human Rights, 160 No. Washington Street, Boston, MA 02114, or call (617) 727-5858.**

**The Department of Mental Retardation will schedule a Human Rights Conference for May of 1988. Details will follow.**

---

## **Advance Registration Form**

**Name:** \_\_\_\_\_

**Address:** \_\_\_\_\_

**Agency:** \_\_\_\_\_

**Special Needs Required:** \_\_\_\_\_

**I request a subsidy. Due to financial hardship, I would not be able to attend without it.**

**I have enclosed a check for \$30.00 payable to MLRI.**

**Return to:  
Office for Human Rights  
Department of Mental Health  
160 No. Washington Street  
Boston, MA 02114**



# Human Rights Newsletter

Volume IV Number 2

July, 1988

## MESSAGE FROM THE DIRECTOR

By Robert J. Foster

An ambulance driver will not take a person to the hospital.

A physician denies treatment for a patient who is seriously ill.

A public assistance official refuses to speak with an applicant.

The stigma of mental illness is more than the occasional joke or poor choice of phrase. The true stories above are only an example of what has happened to over 11 million Americans who have been called mentally ill. Finding a job, securing housing, receiving services, and establishing relationships are adversely affected by the misconceptions and attitudes of others. Recently, at a community residence, nearly everyone had a story. Some told of their attempts to be treated like every other member of their family. Caring staff told of their struggle to recognize and overcome preconceived notions.

On Friday, May 6, 1988, 368 people attended the Department of Mental Health's Fifth Annual Human Rights Conference. They discussed the issue of stigma as well as other topics affecting Human Rights. People had an opportunity to learn and discuss the issues, as well as experience the energy and commitment of others involved in Human Rights.

It is time for society's attitudes to change. Ignorance has been more than inconvenient. It has caused pain and suffering for too many people. This month the Human Rights Newsletter contains a summary of the proceedings of the conference. I encourage you to read what you may have missed and to join the fight against the stigma of mental illness.

Robert J. Foster, M.Ed., M.S.W., is the Director of the Office for Human Rights, Massachusetts Department of Mental Health.

## EDUCATE

HELP PEOPLE TO UNDERSTAND THAT mental illness is a medical illness like cancer, kidney disease, diabetes. The difference is that it strikes the brain. It cannot as yet be cured, but it can be treated.

HELP PEOPLE TO UNDERSTAND THAT people with mental illness don't need to spend their lives in the hospital, any more than a person with diabetes does. They may need periodic hospitalizations when their illness becomes acute, but that shouldn't mean they can't come home when their illness is stabilized.

HELP PEOPLE TO UNDERSTAND THAT Hollywood's depiction of mental illness is just as much a fantasy as their depiction of family life on Dynasty or Dallas. A person with mental illness is no more likely to be violent than any other person you meet.

HELP PEOPLE UNDERSTAND THAT people with mental illness can make good employees. Ask anyone who is in the business of finding steady workers, with low absenteeism and low job turnover.

HELP PEOPLE TO UNDERSTAND THAT people with mental illness can make good neighbors. Contrary to what you may have heard, property values are not affected by a group home in a neighborhood.

## SPEAK OUT

WHEN YOU hear someone making light of mental illness, remind them that these illnesses touch one in four families.

WHEN YOU see a headline or an article that misleads more than it enlightens, write a letter to the editor.

WHEN YOU hear your neighbor saying they don't want "those people" around, remind your neighbor that mental illness can strike anyone, and ask what compassion they would like shown to their own loved ones.

Published by the Office for Human Rights, Massachusetts Department of Mental Health, Robert J. Foster, Director; Vartan H. Artinian, Editor, 160 North Washington Street, Boston, MA 02114. Telephone: (617) 727- 5858.

## FIFTH ANNUAL HUMAN RIGHTS CONFERENCE

By Risa Shames

The Fifth Annual Mental Health Human Rights Conference held on May 6th, at the Royal Plaza Hotel in Marlborough, brought together over 350 people under the title, "Don't Call Me Looney". A vast array of mental health consumers, advocates, legislators, administrators and investigators participated in ten separate sessions, including a grand plenary session in the style of "The Phil Donahue Show."

In the opening session, five panelists and the audience debated the dilemma: how to fight stigma without violating First Amendment rights. With a microphone in his hand and an ample supply of thought provoking questions and witty comments, Tony Winsor, of the Massachusetts Law Reform Institute, was able to keep a lively dialog moving between the panelists and the audience.

Paul Szep, political cartoonist for the Boston Globe, defended his craft against accusations of stigma and discrimination. From his perspective, he has a right to satirize issues and the public has a right to respond with letters of objection. Szep worried that satire would disappear if DMH's Anti-Stigma Campaign succeeds. The publisher will get rid of him; "My First Amendment rights won't matter. I'll be out of work." Kevin Preston, Assistant Commissioner for Community Relations, countered these remarks by defending DMH's Anti-Stigma Campaign as the way for the Department and citizens who are concerned with mental health to end the stigma associated with mental illness. "Stigma will end only if there is a concerted effort to confront people who make such comments. We have to make it socially unacceptable to make jokes about people with mental illness."

Another panelist, Bernie Yadoff, a representative of the Civil Liberties Union of Massachusetts, spoke of the First Amendment's freedom of the press and freedom of speech for all. He voiced his concern about a state agency, DMH, leading a campaign against political satire. He sees this as leading to state action or perhaps censorship. Peggy Maisel, a lawyer with the Center for Public Representation in Northampton, called for legal action to combat discrimination and prejudice.


From the perspective of someone who has been directly

affected by stigma, Pat Deegan of M\*POWER, a mental health consumer organization, said; "Our freedom of speech is eclipsed. We have internalized the stigma because we believe that we have no rights. Mental health consumers must find our own voice and empower ourselves." Her words drew great support and encouragement from the audience. The dialog continued as a forum with audience members posing questions and stating their opinions.

In the afternoon, Keith Rawlins, Chairman of the Human Rights Advisory Committee, awarded the 1988 Human Rights Awards to people who have made outstanding efforts to protect the rights of people with mental illness. Award recipients were Myra Landau, Citizen Mental Health Monitoring Program Coordinator, and the twelve member Human Rights Committee of the Dorchester Counseling Center.

The remainder of the conference was devoted to small group workshops on issues including AIDS, Community Siting, Multi-Cultural Issues, Homelessness, Self Advocacy, and Investigations. The full day conference touched upon so many issues that one almost felt overwhelmed by the scope of human rights in mental health services. However, each workshop focused the topics and each participant was able to get a more in-depth view of topics of interest to them.

Risa Shames is the Assistant Editor of "Connections," the monthly publication of the Department of Mental Health, Office of Community Relations. This article is reprinted by permission from "Connections," Vol. I; Issue 3, June 1988.



The Office of Community Relations has buttons, pamphlets, window decals, and posters to celebrate the kick-off of the Anti-Stigma Campaign. If you are interested in receiving materials, please write to the Office of Community relations, Department of Mental Health, 160 North Washington Street, Boston, MA. 02114.



## HUMAN RIGHTS ADVOCACY AS THERAPEUTIC INTERVENTION

By Sara E. Wright

Is human rights advocacy therapeutic? What specific approaches can be taken to enhance the therapeutic potential of advocacy when working with individuals who have mental illness? These were the subjects of conversation at the workshop, "Human Rights Advocacy as Therapeutic Intervention."

Sara Wright, Human Rights Officer at Danvers State Hospital, spoke philosophically and practically about these issues. She talked about the importance of the exercise of choice in enabling people becoming as fully functioning as they are able to be, which is the ultimate goal of therapy. She talked as well about the constant tension that exists between the legitimate concern of freedom and choice, on the one hand, and protection for people who are ill, on the other. While not denying the appropriate and necessary role of protection in dealing with people who are mentally ill, she stated that the role of human rights is to push on the side of freedom and rights so as to achieve the least restrictive setting that is compatible with the realities of an individual's handicap.

In addition, Ms. Wright cited specific principles that can help ensure that an advocacy interaction is therapeutic, fostering the individual's dignity, self-respect and self-reliance, rather than serving to further disempower. These include 1) listening carefully to the person, their needs, their question; 2) respecting them; 3) providing information, or channeling them to appropriate sources; 4) assisting them in formulating choices and exploring the potential consequences of their actions; 5) empowering self-advocacy; and 6) acting on someone's behalf only as a last resort. She cited examples of the use of these principles in her work.

Jack Reape, Human Rights Officer from the Parker Street Shelter in Boston, brought in the community perspective. Mr. Reape raised some of the tensions and questions that exist in advocacy. For example, there is a tension between the rights of individuals, and the rights of the group, e.g., in a group home, or shelter. Should the rights of the individual always take precedence? How are these issues to be re-

solved? Mr. Reape also pointed out that it is possible for advocacy to be counter-therapeutic when advocacy plays into existing problems.

Finally, Mr. Reape mentioned the role of the Human Rights Committee. Could the Committees be active, in their own communities, in ways that diminish the stigma of mental illness?

Lawrence Fieman, the third panelist to speak and a psychologist on the staff at Danvers, stated that he takes it as a given that good advocacy is therapeutic, and that good therapy respects people's rights. He specified that the Department has two legitimate mandates: social control, and

the treatment of people with mental illness. He believes that human rights advocacy is on the side of treatment, and that it is an important voice to balance with social control. Dr. Fieman went on to speak on specific tools that can be used in advocacy - for example, the use of language, and phrasing

things positively, so that the unconscious of those with whom one works is fed with positive, rather than negative images.

Dr. Fieman responded to a question which led to discussion for the remainder of the workshop. Discussion revolved around two primary axes: the use of language and other dimensions of communication and the tension between rights and protection. Concern was expressed about people leaving the hospital, and injuring themselves or others. Dr. Fieman stated that the general principle of confidentiality of communication between a patient and his/her doctor is overridden if someone is speaking of harming themselves or others, at which point it becomes obligatory upon the therapist to convey this information to the treatment team.

There was discussion as well around the importance of communication: staff to staff, and staff to people with mental illness, and a general sense that if existing laws were enforced we would be in pretty good shape.

Sara E. Wright, M.Div., Ed.M., is the Human Rights Officer at Danvers State Hospital.

**Listen**  
**Respect the person**  
**Provide information or channel to appropriate sources**  
**Assist in formulating choices and exploring consequences**  
**Empower self-advocacy**  
**Recognize the reality of learning from experience**  
**Work together towards the person's goals**  
**Act on behalf of someone only as a last resort**

## SMALL GROUP CONFRONTATION

By Douglas O. Richard

This morning workshop entitled "Small Group Confrontation" focused on ways and means of confronting stigmatizers in small groups. The moderator, Gladys Maged, Director, Court System Gender Bias Study, Massachusetts Legal Services, was joined with Kevin Preston, Assistant Commissioner for Community Relations at the Department of Mental Health.

At the start of the workshop, Ms. Maged asked the participants to break into small groups to discuss terms that commonly stigmatize the people with mental illness. These terms were later shared in a group discussion. The group concluded that phrases, depicting the people with mental illness as either "animals" or "screwballs," are offensive and inaccurate, however, exemplify the stigma that currently exists. Several participants pointed out that the stigma problem goes beyond the use of terminology and can often be identified in body language and tone. Others feel that the perception of the people with mental illness is that they can not be treated as equals in our society. This discussion concluded that a focus on education and community support is needed to combat the stigma problem.

Kevin Preston spoke briefly about the Anti-Stigma Campaign currently underway at the Department of Mental Health. Mr. Preston stated that public education is needed to combat the general perception of the people with mental illness and to increase the level of understanding that currently exists.

Ms. Maged indicated that people generally do not understand the damage they are creating when stigmatizing a group such as the people with mental illness. It was Ms. Maged's feeling that all groups should be given the opportunity to be respected as individuals.

At the conclusion of the workshop, the group was asked to participate in role play situations. Each scenario focused on ways to confront stigmatizers in small groups. The outcome, if practiced on a routine basis, would be an eventual change in the perception of the community at large towards groups of people such as the people with mental illness.

Douglas O. Richard is the Human Rights Officer at Medfield State Hospital.

## COMMUNITY SITING

By Michael Kemp

The "Community Siting" workshop featured Kenneth Margolin, Esq., moderator, Representative Henry Grenier, House Chairman, Local Affairs Committee, Stan Goldman, Esq., Executive Director, Mental Health Legal Advisors Committee, and Robert Nason, Director, Housing Services, DMH.

Representative Grenier contended that to make the path to community residences easier, local officials should be given prior notification of a DMH siting. This notification would include such information as how many people would be living in the home and who could be reached in case of an emergency. Lastly, Representative Grenier stressed that the community siting problems should be addressed by DMH rules and regulations and not by legislation.

Stan Goldman stated that even if the Legislature changed the Educational Use Exemption for community residences, state and federal constitutions and statutes would be interpreted by courts to permit community siting. Mr. Goldman asserted that prior notification to local officials is wrong. Neighbors fear of the unknown, bigotry, and the feeling that these people are "different" would make it difficult for programs to succeed. Mr. Goldman added that how can we presume we have the right to know about DMH neighbors when we wouldn't do it if a Black or Hispanic family bought an adjoining house. In essence, people have no right to abridge the right of others to live where they choose.

Robert Nason stated that the Legislature has provided us with the challenge and opportunity to provide housing. The question involves not if, but when, this will be done. Mr. Nason's pragmatic approach to this issue would be to build as many houses as quickly as possible with quality programs. This in turn would hopefully abate community resistance to these residences. Mr. Nason also encouraged people to speak up when the opportunity presents itself in support of quality residential programs.

Michael Kemp, J.D., is the Human Rights Officer at Metropolitan State Hospital.

**Materials Available**  
**New!** MH Individual Service Plan Regulations.  
 Now applies to all MH programs. Call: (617) 727-5858.



## SELF ADVOCACY AND TEACHING CLIENTS THEIR RIGHTS

By Douglas O. Richard

The afternoon workshop entitled "Self Advocacy and Teaching Clients Their Rights" was presented by Mr. Abe Morochnick, M.A., Community Resource Specialist, and Ms. Judi Chamberlin, Program Director at the Ruby Rogers Advocacy and Drop-in Center.

The focus of this workshop was self advocacy and how the "system" can be a frustration to consumers. Mr. Morochnick spoke on economic factors that leave persons to be exploited while agencies scramble for profit. He stated that this is a violation of human rights whenever it may affect minorities, people with mental illness or working class people. Mr. Morochnick concluded that the goal has to be to make the economic system more humane. Following this, Mr. Morochnick spoke about involving persons with mental illness in the decision making process. This is not only a therapeutic intervention but allows for the person to fight for their rights.

Ms. Judi Chamberlin followed, speaking about the Mental Patients Liberation Front and a handbook that was developed and revised to assist people in self advocacy. This handbook is free of charge to individuals involved in the mental health system and is a valuable asset to assist with understanding the system in general and more specifically, the legal implications as they relate to inpatient care. Ms. Chamberlin stressed that a person should do "what they want for themselves" and that each person is a role model to another.

As people continue to learn the system, network with peers, and become involved in the decision making process, they will become better self advocates.

Douglas O. Richard is the Human Rights Officer at Medfield State Hospital.

**Call (617) 727-5858 to borrow a Video Tape**

**Disabled Persons Protection Act  
DMH Investigation Regulations**

**Train Staff  
About their Duty to protect Persons with  
Disabilities from Abuse**

**Learn How to Report Abuse**

## DISCRIMINATION AGAINST PEOPLE WITH MENTAL DISABILITIES

By Sara E. Wright

"Discrimination Against People with Mental Disabilities" was the topic of an afternoon panel. Mr. Geoffrey Brahmer, Executive Director of the Alliance for the Mentally Ill, began the presentation by giving a brief and troubling survey of the ways in which people with mental illness have been abused through the millennia of human history.

Mr. Brahmer cited the multitude of problems in "the system," for example: 1) poor funding for research into mental illness; 2) the overcrowded and otherwise poor conditions in state hospitals; 3) the shortage of community housing; 4) discrimination in employment; 5) lack of adequate legislation to protect the rights of people with mental illness; and 6) the ongoing problem of stigma. He stated that advocates must keep "long memories" and keep up initiative to force change. "We cannot afford to stop, and cannot forget, until we have achieved success," stated Mr. Brahmer.

Peter K. Chan, the Chief of the Investigations Branch of the U.S. Health and Human Services Office for Civil Rights, was the second speaker on the panel. Mr. Chan spoke of the responsibility of the Office for Civil Rights for enforcing federal statutes and ensuring compliance in settings as diverse as hospitals, nursing homes, home health centers, the Department of Public Health, DMH, etc. Any program that receives federal funds falls under the Office's jurisdiction. This is a very large mandate for 350 staff members, nationwide, and it is very difficult to monitor all situations.

William Crane, Esq., the Deputy Director of the Disability Law Center, spoke on the legal situation regarding disability laws. He stated that anti-discrimination laws apply to any program or activity which receives federal financial assistance, or any public or private place of employment with six or more employees. With regard to enforcement, Mr. Crane stated that the Office for Civil Rights is the appropriate agency to which to turn for enforcement of federal statutes. The Mass. Committee Against Discrimination has the administrative responsibility to enforce state statutes, and remedy incidents of discrimination to which these statutes would apply.

Sara E. Wright, M.Div., Ed.M., is the Human Rights Officer at Danvers State Hospital.

## PROTECTING RIGHTS ON THE SCENE

By Michael Kemp

The "Protecting Rights on the Scene" workshop was moderated by Larry Wheeler, M.Ed., Director of Investigations, Disabled Persons Protection Commission, and speakers included Sandy Fleming, Executive Director, Disabled Persons Protection Commission, Louis Berman, Assistant Commissioner for Hospital Management, and Barbara Ahearn, M.S., J.D., Director of Investigations, DMH Office of Internal Affairs.

Mr. Fleming discussed M.G.L. Chapter 19(C) which established the Disabled Persons Protection Commission to protect disabled adults from abuse. The Commission or an agency within the Executive Office of Human Services will investigate cases of reported abuse. The statute allows anyone who suspects that a disabled person has been abused to report the abuse. Additionally, certain individuals under Chapter 19(C) are "Mandated Reporters" who must report cases of suspected abuse.

Mr. Berman focused on DMH's efforts to upgrade staffing at the State Hospitals. Mr. Berman noted that there has been a doubling in the number of psychiatrists, an increase in nursing recruitment, improved training of staff with the advent of Directors of Staff Development, and Orientation Programs for new employees.

Ms. Ahearn stated that the mission of the Office of Internal Affairs was to oversee the overall direction of investigations in programs operated, funded, or licensed by DMH. Department employees are obligated to file complaints of patient abuse which in turn will trigger an investigation. Ms. Ahearn stressed that the role of the investigator is to be an objective fact finder rather than an advocate, clinician, or policy-maker.

Michael Kemp, J.D., is the Human Rights Officer at Metropolitan State Hospital.

### Address Corrections and Additions

The Office for Human Rights is in the process of computerizing its mailing list. Please notify us by calling (617) 727-5858:

If your address is incorrect

If you receive more than one copy

If you wish to add your name to our mailing list

If you want to be removed from our mailing list

## THE CREDIBILITY GAP BETWEEN PSYCHIATRISTS AND CONSUMERS

by Stephen E. Wall

The workshop, entitled "The Credibility Gap Between Psychiatrists and Consumers," was headed by a distinguished panel which included Joseph Carson of the Ruby Rogers Center and member of the Human Rights Advisory Committee, Brad Evans and Paul Ottenstein of the Ruby Rogers Center, Daniel Billings Fisher, M.D., Medical Director, Eastern Middlesex Mental Health Center, Wakefield, Massachusetts, and Gay Lester, and Rebecca McAuley. The major topic of the panel discussion was stigma and the well meaning professional.

We often hear this word and think only of the overt acts and phrases which smack of prejudice. But after attending this workshop, you get the impression that the subtle discrimination is just as destructive to one's self-esteem.

The panel discussion consisted of a short skit which was representative of a group session. The one theme that permeated the entire hour was that stigma can take many forms and mental illness should not be treated any longer as a "closet illness." Well intentioned professionals should also not be the only people spreading this message. Advocates of all types, mainly former clients, should and will take the lead in this area.

Lastly, each member of the panel gave a brief statement of their experience in the "system" and some of the many obstacles they have had to overcome in order to regain control of their lives.

Stephen Wall is the Human Rights Officer at Northampton State Hospital.

## Certified Community Human Rights Officer

Learn essential skills and basic information

One day format

For all MH Community Programs

Classes held in Worcester, 10am to 4pm

Call (617) 727-5858



---

**DIRECTOR APPOINTED FOR MR OHR**

By Vartan H. Artinian

On March 17, 1988, Amanda Chalmers, Chief of Staff of the Department of Mental Retardation, announced the appointment of Jean E. Tuller to the position of Director of Human Rights for the Department. "In her eleven years of experience within the Massachusetts and New Hampshire mental health and mental retardation service systems," stated Ms. Chalmers, "Jean has developed a foundation of skills and knowledge relative to human rights and advocacy for persons with disabilities."

Ms. Tuller has received her B.A. in Special Education from Southern Illinois University/Edwardsville, in 1976, and a Masters in Public Administration from University of Massachusetts at Amherst in 1985.

During the past eleven years, Ms. Tuller has worked as Special Education Teacher at Belleville Township High School in Belleville, Illinois and as Mental Retardation Professional at Walter E. Fernald State School. She came to the Central Office of the Department of Mental Health in 1984 as an Administrative Intern responsible for assisting with the development, organization, and implementation of the Office for Human Rights. Between March 1985 and November 1986, in her capacity as Client Rights Coordinator for the Office for Human Rights, she was responsible for providing technical assistance to individuals with mental disabilities, families, advocates, and staff in areas related to the rights of people receiving services from the Department. Also, she supervised the Human Rights Officers in state facilities for individuals with mental retardation. In November 1986 Ms. Tuller joined the Office of Quality Assurance of the Division of Mental Retardation where her responsibilities included assisting the Director in developing internal methods of evaluating program quality, and ensuring the effectiveness of current internal evaluating mechanisms. Her most recent accomplishments include the training of service coordinators, managers, service providers, and families in the strengthened MR Individual Service Plan process.

We join Ms. Amanda Chalmers in welcoming Jean to her new role and wish her continued success.

Vartan H. Artinian, Ph.D., is the Human Rights Specialist at the Office for Human Rights in the Department of Mental Health.

---

**MULTI-CULTURAL ISSUES**

By Karen Viveiros

Speakers for this workshop included Kevin Cahill, Director of Meridien Associates, Efrain Fuentes, Director of the DMH Office of Multi-Cultural Services, and Margaret de Monchy, Coordinator of DMH Refugee Assistance Program. The speakers made it clear that the significant behavior of individuals can, and quite often do, differ from culture to culture. Therefore, identification of norms can sometimes be quite different in a cross cultural environment. Providers of services must be sensitive to the values and ideology of consumers.

A salient part of the workshop dealt with value imposition. The provider's spiritual, religious, physical, or political values must not be forced on the person who is the recipient of services. When this is done, there is a distinct danger of "loosing the client." What is considered normal in one culture may be quite abnormal in another. Typical behavior in a given environment may be quite atypical in another. When dealing with multi-cultural issues, it is important to concentrate on strengths rather than weaknesses.

To reinforce the theory associated with different meanings for different people, the audience was asked to participate in an exercise that associate meanings with different words. For example, some may associate the word America with the word powerful, others with democracy, and so on. The responses to the exercise were interesting and effective as a teaching tool.

A presentation of slides drawn by a group of Cambodian children were presented to the audience. The verbal interpretation of the drawings by the children illustrated quite effectively the differences in the points of view of children from various cultures.

The speakers emphasized education as the key. We must understand that cultural issues are important when dealing with the Mental Health population. Therefore, we must make every attempt to understand the significant behavior of various cultures so that we might establish a norm or standard for providing services for persons from different cultures.

Karen Vivieros is the Human Rights Officer at Taunton State Hospital.

---

**The Human Rights Newsletter is now available in large print  
Call OHR at (617) 727-5858 for your copy**

---

# **REGIONAL TRAININGS FOR COMMUNITY HUMAN RIGHTS COMMITTEES AND HUMAN RIGHTS OFFICERS**

SEPTEMBER 10, 1988	REGION I
SEPTEMBER 17, 1988	REGION II
SEPTEMBER 24, 1988	REGION III
OCTOBER 1, 1988	REGION IV
OCTOBER 8, 1988	REGION V
OCTOBER 15, 1988	METRO-BOSTON
OCTOBER 22, 1988	METRO-BOSTON

9:15 A.M. - 4:00 P.M.

The above trainings will be offered by DMH Office for Human Rights.  
Registration information will be mailed by August 15, 1988.

Office for Human Rights  
Department of Mental Health  
160 North Washington Street  
Boston, Massachusetts 02114



---

# Human Rights Newsletter

---

Volume IV Number 3

October, 1988

---

## HOW TO RECRUIT HRC MEMBERS

By Robert J. Foster

Many Human Rights Committees find that at one time or another they experience membership problems. Members have become disinterested; no new members have been added. In response to many questions, we are presenting a method of obtaining new members that has been shown to work.

There are five phases in the successful recruiting process. They are: 1) announce the search for Volunteers, 2) solicit Prospective Applicants, 3) identify Applicants, 4) confirm Prospective Members, and 5) appoint New Members.

Begin the campaign with a general announcement stating that you are looking for new members. Include a very brief positive statement of the work of the committee. Be sure to include a clear and simple process that interested individuals can use to get more information. A phone number that is often busy or goes unanswered will discourage many people. To increase the likelihood of response, send the announcements to a target audience. Inform family members, past service recipients, or people receiving the agency newsletter.

Letters and announcements may raise interest but they often do not result in many volunteers. Begin phase two within one week of the announcement; solicit Prospective Applicants. Ask staff, board members, and committee members for one or two names of possible candidates. Then call the people on this list, tell them what you are asking them to do, and offer to send them some descriptive informa-

tion and an application. Also remember to call anyone who expressed an interest after reading the announcement. Using the phone at this stage is crucial.

If the Volunteers say no, ask them for two names of individuals who might be interested in serving on the committee. In this way you are giving them a choice of either serving on the committee, or providing you with two new leads. You should continue down the list of prospects, asking them to volunteer or to give you two names. Keep calling until you have more Prospective Applicants than you have openings. Some of these people will drop out during the selection process and you don't want to end up short.

The descriptive information that you send is an important part of phase three, namely Identify Applicants.

It should be a clear description of the duties, responsibilities, and time commitment of a new member of your Human Rights Committee. It should not be overly long, or go into the details of the issues. It should, however, have the essential information for an individual to decide if they should join the Human Rights Committee. Also include an application that gives the committee the essential information they will need to make a recommendation.

Within a week after the descriptive material has been sent out, a follow-up phone call should be made to the applicant in order to answer any questions. In phase four, confirming Prospective Members, you

1. Announce the Search for Volunteers
2. Solicit Prospective Applicants
3. Identify Applicants
4. Confirm Prospective Members
5. Appoint New Members



have a good opportunity to encourage, or assist the individual to fill out the application form. If the

#### Resources

Human Rights Committees must have a diverse membership. If you are looking for a particular category, there are some sources that you may find helpful. Attorneys who are new in town, or junior attorneys of larger law firms, are often interested in becoming active in the local community. Call the larger law firms or Mass. Bar Association lawyer referral phone, they will be able to give you some suggestions. The Massachusetts Psychological Association, and the Massachusetts Chapter of the National Association of Social Workers have referral phones that you may find helpful. You may also call the local college or university. Many of them have a community service component that involves their faculty or students. The committee should have primary and secondary consumers, the Alliance for the Mentally Ill, MH Social Clubs, the Ruby Rogers Center, or M<sup>+</sup>POWER. A good committee reflects the community, so include members from various ethnic and racial backgrounds.

applicant has decided not to join the committee, say thanks and ask for two people who may be interested in joining the committee.

Prospective Members may be invited to tour the program or facility, and to meet the Human Rights Officer and perhaps a few of the committee members. While attending a Human Rights Committee meeting is not necessary, it should not be refused if the individual wishes to attend and observe the proceedings. After all, it is a public meeting.

Finally phase five, the list of Prospective Members should be reviewed by the members of the Human Rights Committee and a recommendation made to the person in charge. The person in charge must make the selection for new members from the list submitted by the Committee (Policy 85-8).

Since membership issues are essential to the life of the Committee, they should be a year round task. A Human Rights Committee that takes membership selection seriously will be viable in the future.

*Robert J. Foster, M.Ed., M.S.W., is the Director of the Office for Human Rights, Massachusetts Department of Mental Health.*

## THELMA YARBOROUGH JOINS OHR

As of July 5, 1988, Thelma Yarborough has joined the Office for Human Rights as Coordinator of Human Rights Officers. She will be the central office resource person and supervisor for Human Rights Officers in the state hospitals.

Thelma, who received her doctorate (Ed.D.) in Higher Education Administration/Curriculum Design with minor areas in Modern European History and Research Methods from the University of Maryland, comes to DMH from the academic community. There she was a teacher of various history, literature and heuristic skills improvement courses and administrator, chiefly of inmate education programs.

Although Dr. Yarborough has publications to her credit in many areas, she considers inmate education to be her major research area. Her initial extended contact with Boston and Massachusetts came when she was a post-doctoral faculty research fellow at Northeastern University where she conducted research on Massachusetts post secondary education programs for inmates. She has also served as consultant to several national and state agencies that are concerned with disadvantaged students, prisons, improvement of reading and language skills and various outreach efforts.

Limited experience in mental health — she worked as a psychiatric aide at the Institute for Living in Hartford, Connecticut — has afforded Thelma a feel for the need for human rights of individuals with mental illness. In addition, much of Thelma's past work, in which she has considered education for empowerment and advocacy to be of paramount importance, has also contributed to her bringing the proper mindset to the Office for Human Rights.

### Materials Available

**New!** MH Individual Service Plan Regulations, 104 CMR 16.00. Now applies to all MH programs. Call: (617) 727-5858.



## VOTER REGISTRATION AT STATE HOSPITALS

By Douglas O. Richard, Stephen E. Wall and Sara E. Wright

Voting is a basic right that all eligible United States citizens share. It is not governed by class, race, social prominence or ethnic background but rather each person is given the right to express freedom of choice and to develop opinions relevant to issues affecting their daily lives.

Persons residing in state hospitals may be limited with respect to transportation and access to local polling places. They can, however, be eligible to vote by registering with their particular town or residence and then requesting an absentee ballot. Six persons at Medfield State Hospital have done so recently along with several others in the past.

well. Many people assisted in this process, including the entire Rehabilitation Department and Pat Shaunessey from the Office of Voter Registration in the city of Northampton.

For the first time in decades, a voter registration campaign has been held at Danvers State Hospital. The suggestion was initiated by the hospital's Human Rights Officer. Since then, many individuals and groups joined forces to make the idea a reality, notably, Joseph Collins, Town Clerk of Danvers, the hospital's Rehabilitation Department, the Volunteer Department under the leadership of William Scott, direct care staff, nursing staff and, of course,

### YOUR RIGHTS AS A VOTER

Whether you are voting at the polls or by absentee ballot, you can obtain instructions and assistance for voting. At the polls, an election official will explain how to use the voting equipment. If you are unable to vote because you are physically disabled or are unable to read or to read English, you may have any person you choose or two election officials assist you in marking your ballot or using the voting equipment.

If you are voting by absentee ballot and need this assistance, your witness or any other person can help you vote. For more information about your right to vote, call or write your City or Town Clerk or Election Commission, or Elections Division, Office of the Secretary of State, One Asburton Place, Boston, MA 02108 (617) 727-2828 (800) 462-VOTE (800) 462-8685 (TDD)

Voter registration once again took place at Northampton Hospital. Two years ago approximately 30% of all eligible patients were registered and 20% from that group applied for absentee ballots from their respective communities.

The method used at Northampton State Hospital for this registration was to have an area designated as an official polling place. This was done simply by receiving the signatures of 10 registered voters in Northampton to petition that a registration take place. Once this was done, the city of Northampton sent a representative from the Office of Voter Registration to facilitate the process.

When persons are registered they may then apply for their absentee ballots. Of course, some people do not exercise this right because they do not expect to reside at Northampton State Hospital in November.

Voting at Northampton State Hospital has worked

the Human Rights Committee.

On an afternoon in early October, the town of Danvers released to the hospital, members of the Board of Registrars who assisted all interested patients (who were not under guardianship) in filling out papers to register. All told, over sixty patients participated. Each person was assisted, to complete a form requesting that an absentee ballot be mailed directly to them at the hospital.

People with mental illness are routinely disenfranchised in many aspects of their lives. On this occasion, however, each individual stood as an equal to any citizen of this country. This simple process reaffirmed basic rights of citizenship and conferred dignity, the dignity of equality.

*Douglas O. Richard, Medfield State Hospital; Stephen E. Wall, Northampton State Hospital; and, Sara E. Wright, Danvers State Hospital, are the Human Rights Officers at their facilities.*

**DISABLED PERSONS PROTECTION COMMISSION**

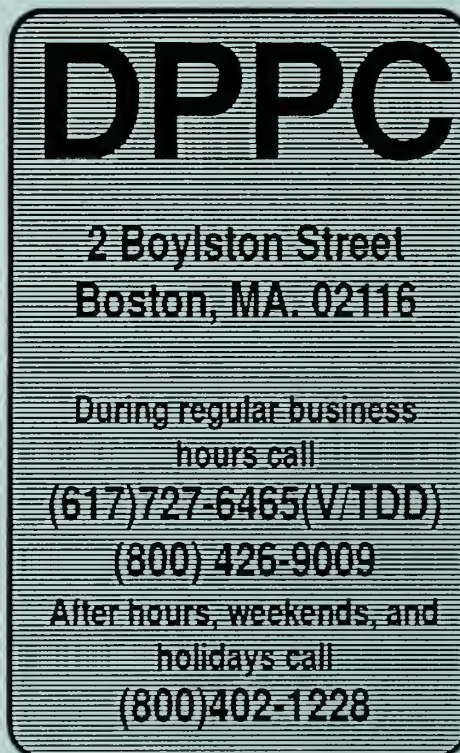
By Constance F. Kane

The Disabled Persons Protection Commission (DPPC) was established by M.G.L. Chapter 19C on March 24, 1987 to receive cases of abuse of adult persons with disabilities and to arrange for protective services when necessary. Reports of abuse can come to the Commission 24 hours a day through its Hot Line (1-800-402-1228) or by calling the Commission's main number from 9-5 (617-727-6465). All persons who suspect abuse of disabled adults should contact the DPPC, and certain professionals, such as, doctors, social workers, teachers, therapists and employees of state agencies within the Executive Office of Human Services must file a report. Failure to report can result in criminal prosecution and a \$1,000 fine.

Reports of suspected abuse are received by the Commission's investigative staff and a determination is made as to whether the situation constitutes an emergency or a non-emergency. In an emergency, the case must be investigated within 24 hours. In non-emergency situations, cases must be investigated within 10 calendar days, and investigation reports must be submitted to the DPPC within those time frames. Protective services must be provided when necessary.

Because Chapter 19C mandates that protective services must be provided when necessary, they are considered an important aspect of the DPPC. This emphasis on protective services places particular importance on the Protective Services component of the Investigation report. In conducting this Assessment, an investigator must determine what protective services are necessary, when they will be provided, and by whom. The principal agencies responsible for delivering protective services, DMH, DMR and MRC, must rely heavily on their existing services to meet the extra protective service demands of

their new protective service caseloads, since only a small allocation was provided to deliver these services. Protective service needs of individuals with disabilities can be very complex and may involve long-term service issues that continue after the need for protection has passed. The DPPC considers protective services to be short-term (generally 90 days) and transitional in nature, and designed to protect the individual from abuse or risk of further abuse.



Since the establishment of the DPPC, the Commission has screened in over 850 cases of suspected abuse. Approximately one half of those cases involve people who are under the care of the state, and the other half involve people who are living in community settings, generally in the care of their families, who do not receive state services. While the Commission is deeply concerned about all reports of abuse, the abuses of persons outside the state system are particularly worrisome because the potential for isolation in these cases makes the identification of abuse, the investigation of an allegation, and the provision of protective services extremely difficult.

In addition to its role in investigating individual allegations of abuse, the Commission may become involved in cases or situations which might have wider systemic implications. The Commission may do this by conducting its own investigations, convening public hearings and preparing written reports of its findings. Examples of some of these activities currently include an in-depth analysis of the Worcester State Hospital investigation conducted by the Department of Mental Health and a review of a recent accident of a physically handicapped person riding the "T."

*Constance F. Kane, Ph.D., is the Director of Protective Services, Disabled Persons Protection Commission.*



## MENTAL HEALTH PROTECTION AND ADVOCACY SYSTEM

By Vartan H. Artinian

The Center for Public Representation (CPR) has been awarded a grant to establish and operate a protection and advocacy (P & A) system for individuals with mental illness in Massachusetts. CPR is located in Northampton and is a nationally known organization in delivering legal services to persons with mental disabilities in residential facilities. Funding for this grant is in accordance with Public Law 99-319, the Protection and Advocacy for Mentally Ill Individuals Act of 1986, enacted by the United States Congress.

The purpose of this Act is to ensure that the rights of people with mental illness are protected while they are inpatients or residents in facilities rendering care or treatment, and for ninety days following discharge from such facilities. The objectives of this grant are being met by operating a statewide system that has the capacity to provide advocacy for persons with mental illness in DMH facilities and to respond to systemic issues. In accordance with Congressional priorities, in grant year one, the program has been serving residents of Massachu-

**NORTHAMPTON STATE HOSPITAL**  
Center for Public Representation  
Maureen Kirk  
(413)584-1644 Ext. 265

**WORCESTER STATE HOSPITAL**  
Legal Services Corp. of Central Mass.  
Jane Quimby  
(508)752-3718 (LSCCM)  
(508)752-4681, Ext. 206 (WSH)

**DANVERS STATE HOSPITAL**  
Mental Health Legal Advisors Committee  
Andrew Laudate (617)723-9130 (MHLAC)  
(508)774-5000 Ext. 206 (DSH)

**METROPOLITAN STATE HOSPITAL**  
Cambridge and Somerville Legal Services  
Stephanie Gilman  
(617)492-5520 (CASLS)  
(617)894-3600, Ext. 3474 (MSH)

**MEDFIELD STATE HOSPITAL**  
**WESTBOROUGH STATE HOSPITAL**  
Mental Health Legal Advisors Committee  
Tom Savage  
(617)723-9130 (MHLAC)  
(508)359-7312 Ext. 231 (Med. SH)  
(508)366-4401 Ext. 375 (Wsb. SH)

**TAUNTON STATE HOSPITAL**  
S. E. Mass. Legal Assistance Corp.  
Loretta Frances  
(508)996-8576 (SELMAC)  
(508)824-7551 (TSH)

Metro Boston CMHC's  
Mental Health Legal Advisors Committee  
Darcy Dumont  
(617)723-9130

setts' state hospitals and mental health centers. In subsequent grant years, depending on funding levels, project resources may be made available to additional groups in community residential facilities, nursing homes, and Department of Public Health facilities.

The statewide P & A system is currently coordinated by Robert Fleischner and Cathy Costanzo, both of the Center for Public Representation. It also has an office in Boston at the Mental Health Legal Advisors Committee. The central component of the program is responsible for coordinating all legal services, staff training, developing and promoting systemic responses to patterns of rights violations, and managing and administering the program. The project has subcontracted with several local agencies to provide services to residents of state hospitals and mental health centers. The programs providing these services, the locations of the local offices, and the names of the P & A persons are in the box on this page.

*Vartan H. Artinian, Ph.D., is the Human Rights Specialist of the Massachusetts Department of Mental Health.*



---

**AN INTERVIEW WITH JUDI CHAMBERLIN****By Sara E. Wright**

"People don't know what it's like to be in a mental hospital when you're a patient there, when you have the keys and when you don't, when you can go home at night and when you can't."

People who do know what it's like to be in an institution have been banding together for mutual support and advocacy since 1971. Forming the "Ex-Patient Movement," they try to carry this perspective and speak out of their experience for the interests of people with mental illness. Judi Chamberlin, the Program Director of the Ruby Rogers Advocacy and Drop-In Center in Cambridge, speaks eloquently for those interests.

Ms. Chamberlin feels her involuntary commitment at a state hospital was unjustified. She feels she was "put in prison for the crime of being depressed." Among other hazards of being caught in the mental health system, she describes the complete loss of autonomy that goes along with being institutionalized. "When I was in an institution I had absolutely no right to decide anything that happened to me, from basic things, like what time I got up in the morning, to really serious things, for example, forced drugging."

Once outside the hospital itself, this loss of autonomy can continue. The Department of Mental Health tries to keep track of its clients, wanting to know where they live and with whom, where they work, how their money is spent. This would represent an intolerable invasion of the privacy that "normal" people expect in their lives, but it is standard practice for people who enter the mental health system.

"If you have a problem today," Ms. Chamberlin states, "and go in and get some help and the problem goes away you should be able to disappear into the community without being identified as a DMH client." It is her experience that this is not often the case. "In some of the community programs, especially, they get into controlling people's money, controlling people's living space... And there is all this interlinkage, so that if you're living in a DMH operated apartment and you're working in a sheltered workshop and you're socializing at a social club, you've got all these different agencies talking

to one another about you. In real life, if you have an argument with somebody at work your landlord isn't going to find out about it. That's seen as somehow therapeutic, but it's very very controlling."

People who come to DMH for help are caught in a double bind: they are encouraged to be open and honest with their doctors and other helpers, and yet these very people have power over their lives, making decisions about commitment, for example, or medication, that the individuals might not want for themselves.

By contrast, in the Ex-Patient Movement, no one has power over another person's life. People may come to the Ruby Rogers Center, which is run entirely by former patients, to talk about their lives and receive support without fear that someone else will use that information to make decisions about their lives that they do not want.

In addition, being trained for as long as they've been in "the system" that someone else is going to decide things for them means that people have not been taught how to solve problems for themselves. As a result, their self-confidence and perception of their own ability has been shattered. She states that people "keep being told that because they're mentally ill they can't do this or that, they're gonna fail, they're no good, all these negative things." By the time they arrive at the Center they have very little self-confidence.

The Center helps people to develop this confidence by giving them support to be responsible for their own lives. There are no "authorities" in the Ex-Patient Movement, simply people working together and learning together who confront similar obstacles and share similar experiences. Ms. Chamberlin states that everyone who comes to the Center has a contribution to make, and finds encouragement for it. She feels the mutual support of former patients helping each other is the primary alternative to the kind of care offered by the mental health system.

Ms. Chamberlin suggests that there are particular options that advocacy groups or concerned indi-



viduals can choose to help carry the attitude embodied by the movement. She suggests that patients and ex-patients could be involved in training staff in hospitals about what hospitalization is like from the patient's point of view. Formalized trainings should also be established to inform patients about their rights, to confirm for them that they do have rights, and that someone is out there trying to protect those rights. People can feel "that they are just this little thing and that there are huge forces coming at them and there's nothing they can do about it." That anything can be done to them and nobody would think twice about it. It is essential, she feels, to let them know that there are legal provisions to protect them and that, if they have a grievance, someone will look into it and take it seriously.

It is also important that the advocacy community help to build patients' self-confidence by working with them to solve problems, rather than rushing in to solve the problems for them. This involves taking time to pull out the regulations, for example, and read them together, helping patients understand the system, how it works, and what options they have. To dash in to "fix things" simply increases the individual's dependence on others and does nothing to further self-confidence or self-reliance.

Finally, the advocacy community must communicate through its attitude that it respects the patients with whom it works. "People have the right to be believed unless you have some really good evidence not to believe them. Don't assume that because they're mentally ill they are not credible. People pick that up, and it's just devastating."

When asked what advice she would like to give to hospitalized patients, Ms. Chamberlin said that she would like them to realize that they are not alone, that there are many other people who have had their experience, people who are not "out of it" and passive and uncaring. There is a community of people who've shared their experience to which they can turn for help. "We care," she concludes, "we care a whole lot. It's our lives, so there's good reason to care."

*Sara E. Wright, M.Div., Ed.M., is the Human Rights Officer at Danvers State Hospital.*

## SARA E. WRIGHT

Sara Wright is the Human Rights Officer at Danvers State Hospital. Sara has worked in many states and nations with disabled people or with individuals in need due to life circumstances. She has worked with the elderly, in a soup kitchen for alcoholics and with severely retarded children in the Virgin Islands. At age 20, she helped deliver babies at a bush hospital in Africa. Immediately before coming to Danvers, she was working with abandoned children in Tegucigalpa, Honduras.

Sara holds a B.A. in Psychology and an Ed.M. and M.Div., both from Harvard University. She hopes, in her role as Human Rights Officer, to act in a way that is respectful of the rights and dignity of staff members as well as clients, while consistently striving to "give voice to the voiceless." She finds that walking that fine line is an extremely challenging and sometimes lonely occupation.

In addition to the daily aspects of her role, Sara is interested in the development of training programs to educate clients and staff in clients' rights. She has developed a video tape for training staff in the Disabled Persons Protection Act. She is also interested in the therapeutic aspects of the Human Rights Officer role. At present, she is co-therapist in an assertiveness training group for assaultive women at Danvers. Through this medium, she helps women find other ways to deal with their emotions and needs than through assaultiveness. She also hopes to develop a therapy group for female clients who are the survivors of sexual abuse, helping them to overcome the role of the victim.

On the whole, Sara speaks of her job as extremely challenging, interesting, unpredictable and occasionally discouraging. Sometimes, she loses sleep over her work.

### Address Corrections and Additions

Please notify us by calling (617)727-5858:

If your address is incorrect

If you receive more than one copy

If you wish to add your name to our mailing list

If you want to be removed from our mailing list

## **Have you Been Certified?**

**Certification Training for  
Human Rights Officers  
from all MH Community Programs**

**Topics include:  
What to Do as a HRO  
How to Have an Effective HRC  
Effective Advocacy Techniques**

**One Day Format  
Classes held in Worcester  
10am to 4pm**

**To Register Call (617) 727-5858**

## **State Hospital Human Rights Officer Directory**

**Danvers State Hospital (413)584-1644 x424  
Sara E. Wright (617)727-0020  
(508)774-5000 x395  
(617)727-9550**

**Medfield State Hospital (508)824-7551 x124  
Douglas O. Richard (617)727-7978  
(508)359-7312 x461  
(617)727-9830**

**Metropolitan State Hospital David Bakalyan  
Michael Kemp (508)366-4401 x2573  
(617)894-3600 x3126  
(617)727-9593**

**Northampton State Hospital Alden Miller  
Steven E. Wall (508)752-4681 x530  
(617)727-0470**

**Taunton State Hospital  
Karen Viveiros  
(508)824-7551 x124  
(617)727-7978**

**Westborough State Hospital  
David Bakalyan  
(508)366-4401 x2573  
(617)727-5506**

**Worcester State Hospital  
A. Raymond (On Leave)  
Alden Miller  
(508)752-4681 x530  
(617)727-0470**

**Office for Human Rights  
Department of Mental Health  
160 North Washington Street  
Boston, Massachusetts 02114**



# Human Rights Newsletter

Volume V Number 1

January, 1989

## 1989 HUMAN RIGHTS AWARDS

By Robert J. Foster

At the Human Rights Conference on May 19, 1989, the Office for Human Rights of the Department of Mental Health will once again recognize individuals who have distinguished themselves through exceptional service or specific actions which have enhanced the rights of people with mental illness. This year we will recognize five categories:

1) For the Outstanding Contribution to Human Rights by a Staff award, we are looking for staff of the Department of Mental Health, or other department or agency, who has consistently contributed to the Human Rights of people in a program managed or funded by the Department of Mental Health, or who has shown an outstanding contribution to Human Rights through an exemplary action.

### Outstanding Contribution to Human Rights by a Staff

### Outstanding Contribution to Human Rights by a Volunteer

### Outstanding Human Rights Committee

### Outstanding Contribution to Human Rights by a Human Rights Officer

### Extraordinary Contribution to Human Rights

by a Human Rights Officer award recipient will be an individual who has performed the duties of a Human Rights Officer in an outstanding manner. This award will be selected by a vote of the Certified Human Rights Officers.

5) The recipient of the Extraordinary Contribution to Human Rights award will be presented to either a person who, through consistent exemplary service over a number of years, has contributed to the Human Rights of people receiving services in a program either funded or managed by the Department of Mental Health, or a person who has contributed, through an exemplary action, to the Human Rights of all of the citizens of the Commonwealth of Massachusetts who have mental illness.

2) The nominee for the Outstanding Contribution to Human Rights by a Volunteer should be unpaid and has consistently contributed to the Human Rights of people in a program managed or funded by the Department of Mental Health, or has shown an outstanding contribution to Human Rights through an exemplary action.

3) The Outstanding Human Rights Committee award will be given to a Human Rights Committee that has distinguished itself in an exemplary fashion. This award will be selected by the Human Rights Advisory Committee.

4) The Outstanding Contribution to Human Rights

We are asking for your assistance to identify individuals who should receive special recognition for their outstanding efforts. Nominations may be made by a supervisor, peer, professional colleague or other individuals familiar with the person's work. An individual may not be nominated by a relative or subordinate, nor may people nominate themselves. To nominate an individual, you must submit the nomination papers and two letters of recommendation by March 3, 1989 to the Office for Human Rights. You may get nomination packages by calling the Office for Human Rights.

*Robert J. Foster, M.Ed., M.S.W., is the Director of the Office for Human Rights.*

Published by the Office for Human Rights, Massachusetts Department of Mental Health, Robert J. Foster, Director; Vartan H. Artinian, Editor, 160 North Washington Street, Boston, MA 02114, Telephone: (617) 727-5858 Voice/TTY.



**GETTING THE WHOLE STORY**  
**(An Interview with Stan Goldman)**  
**By Thelma B. Yarborough**

Stan Goldman, Executive Director of Mental Health Legal Advisors Committee, turns on a warm smile and says, "my overall impression of the operation of the agency is a very good one." "We are following up on a more permanent way to get the right for DMH clients under guardianship to vote." Goldman was referring to a special and successful effort of the Mental Health Legal Advisors to arrange for 19 clients under guardianship to vote in the last Presidential election.

This was just one of a few projects in progress at this very small agency established by the Commonwealth to: 1) make sure that those receiving mental health services can exercise their rights; and 2) provide legal advice on mental health law.

Created in 1973, the Mental Health Legal Advisors Committee (MHLAC) accomplishes its mandates by training lawyers to represent persons with mental illness, maintaining paralegals in three local hospitals and all mental health centers to work with patients in advising them on getting rights and benefits and using administrative and legislative lobbying on proposed policies and legislation involving rights of persons with mental illness.

Though the agency is small, there are three attorneys, four paralegals and some law students serving internships, it is well-known and gets lots of calls each day through its toll-free number (1-800-342-9092) and local number (723-9130). Many of these calls are a result of referrals by clients, families and/or attorneys.

Sometimes, agency attorneys represent clients in actual cases. However, generally most of the clients are represented by private attorneys.

Presently, MHLAC is compiling a list of referrals which should be helpful to all agencies serving persons with mental illness through the Department of

Mental Health. The list promises to be a dynamic one because input will be solicited from many other agencies.

A concern, said Goldman, is that there is less than "two sides of the story" now being heard in guardianship, etc. hearings because clinicians need to be trained for comprehensive input. However, Goldman indicated that this training of clinicians is now a major project of MHLAC so that hearings can be less one-sided for the legal system.

MHLAC is governed by a board of fourteen lawyers

**MHLAC has printed the following publications. While all are available to the public at no cost, a donation to help defray the costs of printing and handling is requested.**

**Training Manual for Civil Commitment**

**Handbook on Guardianship, Conservatorship and Other Options**

**Legal Rights of Developmentally Disabled People in Massachusetts**

**Representing the Mentally Impaired Defendant**

**The Role of the Attorney in Rogers-type Guardianships**

**Your Rights Regarding Medication**

**Your Rights Regarding Restraint and Seclusion**

**The Advisor (MHLAC's quarterly newsletter)**



accept court appointments through the Committee for Public Counsel Services noted above, the central office staff is available to provide expert technical assistance to lawyers and advocates involved with mental disabilities matters.

Each field counsel office, located on the grounds of a state hospital or mental health center, is staffed by a specifically trained paralegal or law student/intern. All are supervised by an attorney.

In addition to casework advocacy, field counsel staff are often involved in training sessions for institution staff and patients on issues such as guardianship, the right to treatment, the right to refuse treatment, etc. They are also available to provide legal information to staff and family members on individual cases. All information pertaining to individual clients is, of course, strictly confidential.

MHLAC is an integral part of the Massachusetts component of the federal Mental Health Protection and Advocacy Project. Funded under the Protection and Advocacy for Mentally Ill Individuals Act of 1986, the Project's focus is to protect residents of mental health facilities against abuse and neglect and to protect and advocate for such resident's legal rights.

The Disabilities Benefits Project provides legal representation and assistance to persons who are mentally disabled and who may be eligible for federal disabilities benefits (SSI and SSDI). The disabilities benefits paralegal, supervised by an attorney, will assist persons who are unable to afford a lawyer to obtain benefits for which they are eligible.

**Sixth Annual  
Human Rights Conference  
"A.I.D.S. and HUMAN RIGHTS"  
Friday, May 19, 1989  
Royal Plaza Hotel  
Marlborough, Massachusetts**



## THE INDIVIDUAL SERVICE PLAN REGULATIONS

By Jan Nisenbaum

Individual Service Plan (ISP) Regulations, 104 CMR 16.00, are now in effect for the Department of Mental Health. These Regulations, promulgated last spring, reflect the department's commitment to ensure that service planning occurs in a consistent manner across the state.

The ISP Regulations set a conceptual and legal framework for conducting Preliminary and Comprehensive Assessments, developing individual service plans, and establishing procedures for appeals. The Regulations provide an important foundation for the department's case managers in carry-

and reviewed; and by which an individual and certain others may appeal the provision or denial of mental health services.

In addition, the ISP Regulations have been established to ensure that the department provide, purchase, arrange, monitor, and coordinate services which are, to the maximum extent possible, adequate, appropriate, consistent with the client's needs and least restrictive of the client's freedom. Another purpose of the Regulations is to ensure that mental health services are planned and provided in an individual, rational, and fair manner with the full-

### **The ISP Regulations set standards:**

- \*by which an individual may request or be referred to and/or receive mental health services;**
- \*by which an individual is determined to need mental health services;**
- \*by which an individual receives a comprehensive assessment and individual service plan;**
- \*by which an individual service plan and the program specific treatment plans are monitored and reviewed; and**
- \*by which an individual and certain others may appeal the provision or denial of mental health services.**

ing out their responsibilities to develop individual service plans and assist clients in accessing appropriate services.

The ISP Regulations set standards in the following areas: by which an individual may request or be referred to and/or receive mental health services; by which an individual is determined to need mental health services; by which an individual receives a comprehensive assessment and individual service plan; by which an individual service plan and the program specific treatment plans are monitored

est participation of the client.

The Preliminary Assessment called for in the Regulations is to be performed by a qualified clinician. This assessment shall determine whether the individual needs mental health services, whether the individual should be referred for case management services, whether the individual needs interim services and whether the individual is in the correct area of responsibility.

Case management services and a comprehensive



assessment are available to individuals who "suffer from a serious, long-term mental illness that includes a substantial disorder of thought, mood, perception, orientation, or memory which grossly impairs judgement, behavior, capacity to recognize reality or ability to meet independently life support needs of food, shelter, clothing, management of finances, and health care...". A child or adolescent through the age of eighteen, is eligible for case management if the individual is seriously mentally ill or emotionally disturbed, is referred for inpatient psychiatric services, is covered under Executive Order 244 or is referred under the Medicaid Psych Under 21 Program.

Once the individual is determined to meet the eligibility criteria a comprehensive assessment is initiated. This assessment is coordinated by the case manager and covers the following areas:

- \* mental health status;
- \* social settings;
- \* physical health;
- \* daily living skills;
- \* criminal justice history;
- \* vocational and employment history;
- \* education and training;
- \* preferred language;
- \* legal status; and
- \* resource availability.

The comprehensive Assessment identifies the client's strengths and those areas in which the client needs assistance. This report becomes the basis for development of an Individual Service Plan.

The Individual Service Plan identifies the optimal services which reflect the client's needs without reference to existing resources. The plan identifies the available services, service providers and start dates for service. The individual service plan is developed with the full and active participation of the client, his/her legal guardian, if any, and/or the client's designated representative. The active involvement of the client in setting goals and identifying need areas and preferred services is critical to empowering our clients and ensuring that services provided are more effective to meet the needs of the

individual. The Regulations provide the client with the right to accept or reject some or all of the services identified in the ISP.

In addition, the ISP Regulations set forth a process for appeal. A client or guardian may appeal the following: 1) whether the decision regarding the individual's needs for mental health services, comprehensive assessment, case management or an ISP has a reasonable basis; 2) whether the assessments obtained or arranged by the program or case manager to serve as the basis for the development of the ISP are necessary and sufficient to meet that purpose; 3) whether the findings with regard to the individual's capability in fact, legal competency, and the need for guardianship or other protective services are consistent with 104 CMR 15.03 (10); and 4) whether the goals, services and timelines identified in the ISP are reasonable and appropriate. Appeals may also be made on the basis of whether the recommended services are adequate, appropriate, consistent with the client's needs and least restrictive of the client's freedom and whether the timelines for developing the ISP have been followed.

The appeal process includes an informal conference, a fair hearing, a rehearing, and judicial review. The process is fully described in 104 CMR 16.11.

*Jan Nisenbaum, M.S.W., is the Director of Program Development, Central Office, Massachusetts Department of Mental Health.*

*Ms. Nisenbaum is a 1988 recipient of the Commonwealth's Pride in Performance Award. Pride in Performance Awards are given each year to state employees who demonstrate extraordinary skills and commitment everyday in their jobs.*

## Materials Available February 1989 Issue

**MH Individual Service Plan Regulations,  
104 CMR 16.00. Now applies to all MH  
programs.**

**New! Articles from Human Rights News-  
letter.**

**Call: (617) 727-5858.**

## Human Rights Seminars Winter Series

This winter, the Office for Human Rights will present a series of seminars concerning Human Rights for persons with mental illness and some attendant issues. Following, is a listing, with presenters, of those seminar topics:

### Human Rights Issues of Language, Culture and Trauma for the Refugee/Immigrant Client

This seminar will begin to address the particular problems encountered by institutions, service providers and patients alike. Demographics, cultural beliefs, mental health perceptions, contextual understanding of trauma experiences, and the acculturation process will be presented. Significant barriers to treatment and care will be identified and proactive approaches to managing more effectively, including information about available resources, will be provided.

Presented by Efrain Fuentes, Ed.D., Office of Multi-Cultural Services or Margaret deMonchy, B.A., Refugee Assistance Program.

Wednesday, February 15, 1989 ..... Metropolitan State Hospital, Staff Development Classroom, Furcolo Building  
 Wednesday February 22, 1989 ..... Worcester State Hospital, Chapel Hall, Bryan Building, Sixth Floor  
 Wednesday, March 1, 1989 ..... Northampton State Hospital, G Building, AP2  
 Wednesday, March 15, 1989 ..... Westborough State Hospital, Sharp Building, First Floor Conference Room  
 Tuesday, March 28, 1989 ..... Danvers State Hospital, Administration Building, Piano Room  
 Wednesday, March 29, 1989 ..... Medfield State Hospital, Clark Building, Second Floor Conference Room

### Human Rights and Informed Consent/Guardianship

This seminar defines "informed consent" from the legal perspective; discusses the issue of competency to provide informed consent, in general, and competency to provide such consent to treatment, in particular. Also discussed are the practical and procedural issues which pertain to guardianship.

Presented by: Stan Goldman, J.D., Executive Director, Mental Health Legal Advisors Committee

Tuesday, February 14, 1989 ..... Westborough State Hospital, Sharp Building, First Floor Conference Room  
 Thursday, February 23, 1989 ..... Medfield State Hospital, Clark Building, Second Floor Conference Room  
 Wednesday, March 8, 1989 ..... Northampton State Hospital, G Building, AP2  
 Wednesday, March 22, 1989 ..... Worcester State Hospital, Bryan Building, Chapel Hall, Sixth Floor  
 Tuesday, April 25, 1989 ..... Danvers State Hospital, Administration Building, Piano Room

### AIDS and Human Rights

One of the most important challenges for mental health professionals at this time is to teach clients about AIDS and adequate forms of risk reduction as well as their human rights in the DMH system regarding AIDS. Clients who are mentally ill exhibit impaired judgment, increased risky behavior (drug use, unprotected sex, inadequate hygiene), non-compliance with treatment regimes, poor impulse control, poor concentration, cognitively impaired and short attention spans. Adding to their vulnerability are environmental stressors, such as poverty, homelessness, unemployment, lack of family support and societal prejudices.

This presentation will give information on basic routes of transmission, risk reductions and film previews. Topical discussions will be held using the assertive approach with basic counseling skills.

Presented by: Rita Martin, B.S., R.N. AIDS Coordinator, DMH.

Thursday, February 16, 1989 ..... Danvers State Hospital, Administration Building, Piano Room  
 Thursday, February 23, 1989 ..... Taunton State Hospital, Chambers Building, Auditorium  
 Wednesday, March 1, 1989 ..... Medfield State Hospital, Clark Building, Second Floor Conference Room  
 Wednesday, March 15, 1989 ..... Metropolitan State Hospital, Furcolo Building, Staff Development Classroom  
 Wednesday, April 5, 1989 ..... Northampton State Hospital, G Building, AP2  
 Wednesday, April 19, 1989 ..... Worcester State Hospital, Sixth Floor Bryan Building, Chapel Hall

*All seminars are scheduled for 1:00 to 4:00 pm. No registration is required.  
 Admission is free. Sign Language interpreters are available on request (617) 727-5858 Voice / TTY.*



---

**NEW HRO AT WESTBOROUGH STATE HOSPITAL**

---

David Bakalyan is the most recent addition to the family of D.M.H. facility Human Rights Officers, accepting the post at Westborough State Hospital in October, 1988.

From Westfield State College, Mr. Bakalyan earned a Bachelor of Arts degree in Mathematics with a certificate in education, qualifying him to teach high school grades nine through twelve. He also holds a minor in psychology and has completed studies in world philosophies and religion. He is currently setting goals to complete a graduate degree in educational psychology, where he is focusing on the connection between learning and student self-perspective.

David carries the use of this concept in his presentations in Human Rights to the Hospital's employees. He takes them all on a brief trip into the lives of people with mental illness. Bakalyan says, "A lot of the time, an event might seem simple enough to me, yet it may be perceived to be complicated or disconnected or restrictive or even intrusive by you. Until I take time to see with your eyes, I will never really begin to understand you, and I will never give myself the opportunity to learn that you too, are fully human."

During his college years, David held various stu-

dent-teaching and student-intern positions. In November, 1986, he was employed by Pioneer Developmental Center, Inc., a community-based vendor agency for the Holyoke/Chicopee Area of the Department of Mental Retardation. Hired as a skill-developer, he soon acquired the position of client program coordinator/recreation services coordinator.

Leaving Pioneer Developmental Center in the summer of 1988, David was caught up in the long arduous search to fill the vacant H.R.O. slot at Westborough, finally landing the position in October. Jumping right in and learning the ropes while actually doing the job, he likens his experiences to the task of trying to braid a clothesline and play jump-rope with it at the same time. He gives thanks to Cathy Samko, who was the acting Human Rights Officer until October, 1988, and to the other facility officers who have provided much insight and support.

Some of his goals are the tasks of reinvigorating his Human Rights Committee, and developing a protocol between the H.R.C. and the Hospital's administration.

We welcome David in his new position and wish him continued success.

---

**ACTING HUMAN RIGHTS OFFICER AT WORCESTER STATE HOSPITAL**

---

Between October 19, 1988 and January 23, 1989, Alden Miller was the Acting Human Rights Officer at Worcester State Hospital, temporarily replacing Antoinette Raymond who was on maternity leave.

Mr. Miller has a degree in Legal Advocacy from the University of Massachusetts at Amherst and is presently pursuing course work leading to an M.Ed. at the Extension site of Cambridge College in Northampton. While at U/Mass., Alden was not only the A.C.L.U. chapter founder-coordinator but was also very actively involved in the "University Without Walls" program, designed to assist self-directed older students seeking credit for adult life

experience and professional experience. As a result of his activities, he was named an "outstanding student leader" by U/Mass. Chancellor Joseph Duffey.

Prior to his coming to Worcester State Hospital, Alden was the Assistant Program Director for a large mental health residential program in Northampton. Also, he has been a Community Human Rights Officer for four years.

"I have an interest in backing the rights of the little guy", says Alden. "It's important to be there when you're needed, and Human Rights is an excellent field to be able to do that."

# STATE HOSPITAL HUMAN RIGHTS OFFICER DIRECTORY

Danvers State Hospital ..... Sara E. Wright ..... (508)774-5000 x395  
 ..... (617)727-9550  
 Medfield State Hospital ..... Douglas O. Richard ..... (508)359-7312 x461  
 ..... (617)727-9830  
 Metropolitan State Hospital ..... Michael Kemp ..... (617)894-3600 x3126  
 ..... (617)727-9593  
 Northampton State Hospital .... Steven E. Wall ..... (413)584-1644 x424  
 Taunton State Hospital ..... Karen Viveiros ..... (508)824-7551 x124  
 ..... (617)727-7978  
 Westborough State Hospital .... David Bakalyan ..... (508)366-4401 x2573  
 Worcester State Hospital ..... Antoinette Raymond ..... (508)752-4681 x530

## HUMAN RIGHTS AREA OFFICE COORDINATOR/OFFICER DIRECTORY

Metro-Boston ..... Judy Laughery .... 617-726-3842  
 REGION I  
 Berkshire ..... Nancy Brenner .... 413-443-7361  
 Franklin-Hampshire ..... Dennis Griffin ..... 413-586-4948  
 Holyoke-Chicopee ..... David Marks ..... 413-594-9141  
 Springfield-Westfield ..... Tony Brown ..... 413-781-0526  
 REGION II  
 North Central ..... Joel Green ..... 508-345-0691  
 South Central-Blackstone Valley ..... Robert Latoucha .. 508-473-6990  
 Worcester ..... Kevin Howley ..... 617-727-0470  
 REGION III  
 Danvers-Salem/Cape Ann ..... Burnham Riggs .... 508-927-4466  
 Eastern Middlesex/Tri-City ..... Hillary Hardy ..... 617-727-0590  
 Lawrence/Haverhill-Newburyport ..... Ligia Dapolito ..... 508-685-3751  
 Lowell ..... Julie Grecoe ..... 617-727-5658  
 Lynn ..... Mary Ann Zampell 617-727-7054  
 REGION IV  
 Cambridge-Somerville ..... Louise E. Dussault 617-491-0600  
 Central Middlesex ..... Stephen Smith .... 508-369-8427  
 Marlborough-Westborough-SouthMiddlesex Ann Pope ..... 508-481-4347  
 Newton-South Norfolk ..... Fran Gately ..... 617-727-3119  
 South Shore-Coastal ..... Juliet Willoughby 617-727-1250  
 REGION V  
 Brockton ..... Linda Lundin ..... 617-727-7905  
 Cape Cod and the Islands ..... Joe Hogan ..... 508-775-1199  
 Fall River ..... James Hornby ..... 508-678-2901  
 New Bedford ..... Janet Kim ..... 508-999-1200  
 Plymouth ..... Robert Daly ..... 508-747-1500  
 Taunton-Attleboro ..... Ted O'Brien ..... 508-824-7551

## Have You Been Certified?

Certification Training for  
 Human Rights Officers  
 from all MH Community Programs

Topics include:  
 What to Do as a HRO  
 How to Have an Effective HRC  
 Effective Advocacy Techniques

One Day Format  
 Classes held in Boston  
 10am to 4pm

To Register Call (617) 727-5858

Office for Human Rights  
 Department of Mental Health  
 160 North Washington Street  
 Boston, Massachusetts 02114





